

**AN EXPLORATION OF THE THERAPIST'S
EXPERIENCE OF PSYCHODYNAMIC
PSYCHOTHERAPY WITH PEOPLE
WITH LEARNING DISABILITIES**

Declaration

This thesis is submitted in partial fulfilment of the requirements of the Doctorate in Clinical Psychology at The University of Sheffield.

The author confirms that the work submitted is her own, and that the appropriate acknowledgements have been made to the work of others where collaboration has taken place.

This work has not been submitted to any other establishment or for any other degree.

Word Counts Page

Thesis format

The literature review contained in this thesis has been prepared in accordance with the author guidelines for the Journal of Applied Research in Intellectual Disabilities (see Appendix A).

The report section conforms to the requirements of Option B of the guidance for preparation of thesis for the Doctorate in Clinical Psychology. The report is therefore written to the format for the Journal of Applied Research in Intellectual Disabilities. The choice of journal was approved by the Research Tutor (see Appendix A)

Word count

Given below are word counts for each of the sections within the thesis. Actual word count is followed by the criteria for the length of each section:

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Abstract

This thesis explores the field of psychotherapy with clients with learning disabilities. The work is organised into three sections:

Part One: Literature Review. The review examines the available literature on psychotherapeutic contact with people with learning disabilities. The emphasis is on exploring the attitude of the profession towards such clients and charts the move from exclusion to partial inclusion. The review then explores in greater depth, the experience of providing therapy to this client group. The review notes the paucity of information on the topic and concludes that access to services has been affected by the stigmatised identity of the group. The spoiled identity associated with learning disabilities appears to be a central focus in the client-therapist relationship.

Part Two: Research Report. This section describes a qualitative study exploring therapists' experience of providing therapy to this client group. Personal accounts were elicited from eleven therapists using a semi structured interview. Data were analysed using the principles of Interpretative Phenomenological Analysis (IPA). Super ordinate themes emerged, relating to the similarities and differences with other client groups, and the experience of working with stigmatised clients. Themes were identified and theoretical links made with prior case descriptions.

Part Three: Critical Appraisal. This section gives a detailed critique of the study's methodology, and explores limitations, clinical implications and directions for future research. A personal account the research process is given, including learning outcomes.

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Stigma and Psychotherapy:

An exploration of the relationship between psychodynamic psychotherapy, psychotherapists and people with learning disabilities.

Abstract

Background: People with learning disabilities have limited access to psychodynamic psychotherapy. This review explores factors which may underlie this exclusion.

Method and Materials: An automated search was conducted using the Psychinfo and Web of Science databases. The library of the Tavistock Clinic was also screened. Combinations of key terms including; “learning disabil”, “intellectual disabil”, “mental handicap”, “mental retardation”, “psychodynamic”, “psychotherap”, and “transference” were used to elicit data. These were then used as sources for further references.

Results: Findings showed ineligibility due to cognitive limitation has been challenged. Effectiveness of psychodynamic psychotherapy is not proven by available research, but findings tentatively support the applicability of the method. Stigma, projection and negative counter transference are all noted in work with this client group.

Conclusions: The available evidence does not support the conclusion that exclusion is justified on the grounds of ability, suggesting the profession may be responding to the stigmatised identity of people with learning disabilities.

Introduction

“They represent such an extreme of life that we wonder whether they are human at all, in any way like us. Our interaction with them seems so minimal, we wonder what the point of their existence is... we do not know who we are for them, or who they are for us. Is there any mutual identity we can establish, any reciprocity between us, and if there is, do we want to know about it?” Ryan and Thomas (1980, p. 13)

In 1993, Bender wrote an article charting what he described as a history of therapeutic disdain towards people with learning disabilities. He identified structural factors in the development of professions and services which acted to exclude this client group. Bender argued that the principles underlying the exclusion were prejudicial rather than empirical. The aim of this review is to explore the claim by looking at the rationales for exclusion from psychodynamic psychotherapy, going on to examine the social identity of this group, and the impact this may have had upon their inclusion in services. Finally, the review will examine the available literature on the therapeutic relationship with people with learning disabilities, with particular reference to counter transference issues which are raised.

To explore Bender's (1993) claim, one needs to look at the validity of the rationale underlying the exclusion. Ineligibility might be argued from two positions; that specific features related to the condition of learning disability renders people unable to make use of psychotherapy; and empirical evidence from psychotherapeutic interventions that demonstrates failure of the techniques with this population.

Before addressing these key questions, it is useful to explore how contributions to the literature emerged. To do so requires a brief history of psychotherapy with people with learning disabilities, as in many ways its evolution dictated the nature of the literature which emerged.

In the course of the review I shall be referring to clients as people with learning disabilities as the preferred term identified by service users. The word “handicap” will be used in the text as a term relating to specific theories.

Brief History

In Britain, literature on psychotherapy with people with learning disabilities did not emerge until the 1980's when Neville Symington was credited with writing the first published description of psychotherapy with a client with learning disabilities (Symington, 1981). Symington's paper marked the beginning of significant interest in this neglected client group. He began a workshop for therapists interested in work with people with learning disabilities at the Tavistock Centre in London. One of the clinicians influenced by this group was Valerie Sinason. Sinason was initially a child psychotherapist who, like a number of authors in the field, moved into working with people with learning disabilities from a different therapeutic speciality.

In 1992, Sinason published an influential collection of case studies. These cases illustrated the clients' emotional intelligence and made a case for their ability to engage with psychodynamic psychotherapy. Sinason's writing was hugely influential (Hodges, 2003, Simpson & Miller, 2004). Work in the field was virtually non

existent, but Sinason's anecdotal, narrative style challenged the views on this client group's suitability for treatment in a way that engaged interest amongst clinicians. The emphasis for much of the available work did appear to be to raise the profile of the population and to inspire other clinicians.

Training initiatives by the Tavistock and from clinicians at St Georges Hospital saw more therapists taking on clients with learning disabilities. The development may also have been assisted by the *zeitgeist* of the 1990's when institutions were being closed, with only 3,000 residents in 1999, in comparison to 70,000 in 1970. (Hollins, 2000). Clinicians were faced with needing to offer interventions to people coping with the complexities of community settings, with the increased emphasis on choice and inclusion which culminated in the government white paper "Valuing People" (2001). In addition, there was a growing awareness of the widespread abuse of people with learning disabilities which demanded a response and provided a focus for early cases (Turk & Brown, 1993).

Small pioneer services began to emerge, where individual practitioners had fostered an interest in this manner of working. Neville Symington's workshop blossomed into a dedicated psychotherapy service for people with learning disabilities in 1995 (Hernandez-Halton *et al*, 2000). Interest was also growing elsewhere, and clinicians Nigel Beail and Pat Frankish established a similar service in the north of England.

The publications generated at this time placed emphasis upon describing therapeutic approaches and sharing adaptations to the therapeutic techniques to accommodate the specific difficulties of the client group (Butz *et al*, 2000). The focus appeared to be

moving from whether the work could be done, to *how* it might be done. Attempts to address this came in the publication of practical technical handbooks (Conboy-Hill, 1992; Hodges, 2003). Although in 2000, Hollins and Sinason still judged the provision of psychotherapy services to be inadequate, the use of this therapeutic approach was sufficient to allow critical reviews of the practise to begin appearing in the literature (Beail, 2003; Willner, 2005; Sturmey, 2005). For the first time there was starting to emerge a literature of psychotherapy with people with learning disabilities from which to consider the question, “*should* it be done?”

The literature included in this review is largely drawn from the references supplied from the search of the Psychlit and Medline data bases with additional material being drawn from searches of the Tavistock Centre Library and local clinical libraries. These sources in turn yielded relevant references which were then pursued. The available literature is very limited. In particular, the search yielded no references which explicitly stated reasons why people with learning disabilities were excluded from psychodynamic psychotherapy. This may be because, in line with the marginalisation of this group, the thought of offering therapy was never entertained so a justification of exclusion was superfluous. Therefore, literature drawn from the broader field of learning disability research relevant to possible exclusion criteria has been included.

As the latter half of the review explores the exact nature of the individual relationship with clients with learning disabilities, information has been drawn from the few existing case descriptions which included therapists’ accounts of their experiences

and reactions. The outcome studies included represent the few systematic investigations and reviews available in the literature.

The Role of Intelligence

The Diagnostic and Statistical Manual (fourth edition) defines learning disabilities as:

“Significant subaverage general intellectual functioning accompanied by significant deficits or impairments in adaptive functioning with onset before eighteen.” (p. 28)

The distinguishing factor between this and other conditions which might involve early onset or impairments in functioning is clearly the cognitive element of the definition. The question of whether intelligence is a required pre-condition for psychotherapy then becomes central. Freud (1904) believed that some degree of intelligence was required for psychotherapeutic gain.

However, Freud’s exact reference to requirements was, “a certain measure of *natural* intelligence” (p. 254). Whilst Freud’s definition may have been interpreted as concomitant with cognitive intelligence, other forms of intelligence have been identified by clinicians pressing for inclusion.

Stokes (1987) introduced the concept of emotional intelligence to describe clients’ ability to engage with the emotional tasks of therapy. Hodgetts (1985) had previously noted that, even where a learning disability clearly existed, the range of competencies encompassed by intellectual impairment made a unidimensional model inadequate

and too ill-defined to allow for blanket ineligibility. This view was supported by Hedlund and Sternberg's (2000) review, which identified emotional, social and practical intelligence as previously unrecognised aspects of adaptive functioning.

Not only has the concept of intelligence been challenged, but so too has the assumption of its aetiology. A number of therapists have questioned the assumption that loss of intelligence is solely due to organic causes. Intelligence has been defined as;

“The capacity of the individual to act purposefully, to think rationally and to deal effectively with his environment.” (Wechsler, 1944, p. 3)

As such, intelligence has a self preservative function. It has been argued therefore if losing knowledge protects the self, presenting as learning disabled can be a paradoxically intelligent act (Sinason, 1992).

Symington (1981) explores the notion that a person may perceive intelligence as threatening and seek to reject this ability and Mannoni (1973) had previously referred to psychodynamic causes of learning disabilities. Morelle (1999) describes clients who withdraw into mutism when demands are made for emotionally challenging responses, thus presenting as less able than they are.

Stokes (1987), whilst recognising the reality of organic damage, encapsulates the phenomenon as the “exaggeration of handicap as a defence” (p. 2). Sinason (1986) categorised this as one of a range of *secondary handicaps*, in which features of the primary, or organic handicap are expanded as a defensive strategy. The proposal that

handicap was exaggerated as a form of defence was formulated as a parallel to Bion's (1967) distinction of psychotic and non-psychotic elements of the personality. It was proposed that there was a distinction between a more disabled part of the personality, and another, more perceptive and able part which was submerged for much of the time. Stokes (1987) described this as an attempt to deny the disability by exerting control over it. By manipulating some aspects of disability, this reinforces the phantasy that the entire disability is elective, and therefore acts as a defence against painful impotence. Stokes also proposed that this defence protected people against emergent violent or sexual feelings, perceived as threatening.

Sinason identified additional functions of loss of intelligence (Sinason, 1986, 1992). *Opportunistic handicap* was a phrase first coined by Sinason (1986) to cover the use of a disability to express hostility and anger. In her 1995 paper, "Revenge and Learning Disability", she proposed that a painful awareness of disability can result in hatred and attacks upon the self or others. She described a boy who despoiled his school's games and toys by pushing his penis into them. In therapy he confessed that:

"They (meaning his parents) made me come out silly and I am going to give all the toys Down's syndrome." (p.17)

Opportunistic handicap would allow the person to disguise such aggressive and envious attacks as part of a disability, rather than as intentional acts.

The last subdivision of secondary handicap was that of its use as a *defence against trauma*. Sinason (1986) reported case examples where a general loss of knowledge

was used in this way to lose the awareness of traumatic events such as previous sexual abuse and rejection. Hollins and Sinason (2000) have recently expanded the definition of trauma to include the disability itself.

Thus, rather than being a criteria for exclusion, loss of intelligence might legitimately have been considered an indicator for the presence of debilitating defences in some cases, and thus highlighting a need for intervention. This might have been dismissed as recent knowledge in relation to the debate upon eligibility for psychotherapy, but the strategy of losing knowledge to protect oneself is actually a central tenet of Freud's (1920) work, as indeed, was the concept of secondary gain which was expanded into the concept of secondary handicap.

Support for the validity of the concept of emotional intelligence in the context of psychotherapy for people with learning disabilities comes largely in the form of case descriptions with little empirical evidence. This remains an obvious source of criticism in much of the available literature. Bichard *et al* (1992) did attempt to measure outcomes using projective drawings in a creative attempt to capture post therapeutic psychological adjustment which reflected emotional maturity. Whilst findings appeared to support the assertions of increased maturity, there remain inherent difficulties with the reliability of this method of assessment (Lowenthal, 2001)

Outcome Studies

The most striking feature of the literature critically reviewing psychotherapeutic interventions with people with learning disabilities is that it is almost completely absent in a field where writing is usually prolific. Orlinsky and Howard's (1986) review of mainstream psychotherapy publications identified 1100 case descriptions over thirty five years. In contrast, Whitehouse *et al's* (2006) review yielded 25 publications where work related to clients with learning disabilities.

Once the approach became more established, the need for systematic outcome studies became apparent (Hurley, 1989). The existing literature was either anecdotal case studies or technical accounts where structural elements of the work might be given, but surprisingly little detail of exactly how the work was done (Frankish, 1989; Symington, 1981).

Beail addressed this shortfall in a series of outcome studies. In his review of the field in 1995, Beail noted that there was a dearth of outcome studies providing evidence for the effectiveness of psychotherapy with the client group. Of reports of work with twenty three clients, only nine cases included outcome data. He proceeded to address this with a series of studies investigating differing ways of assessing outcomes and appropriate means for such evaluation (Beail, 1998, 2000, 2001, 2003).

In a pilot study, Beail and Warden (1996) reported on the outcomes of psychodynamic intervention with ten clients with learning disabilities. Clients were seen for a mean of eighteen sessions. Pre and post measures were taken including the

Rosenburg Self Esteem Checklist (Rosenburg, 1965) and the Brief Symptom Checklist (Derogatis, 1975). These commonly used self report measures were adapted for use as interview schedules to overcome the cognitive disadvantages of the participants. In this study, the measures showed a rise in self esteem and fall in symptomology after the treatment.

Beail was also interested in investigating other outcomes of psychodynamic psychotherapy. He noted that interpersonal difficulties were commonplace in the presentation of people who were referred, but changes in interpersonal difficulties were not measured. He adapted the Inventory of Interpersonal Problems – 32, (Barkham, Hardy & Startup, 1996) for use as an interview (Beail & Warden, 1996) and subsequently used it to show changes following psychotherapy (Beail, 2000).

However, a difficulty of applying and adapting measures for the learning disabled population was illustrated by concerns about the psychometric properties of the measure in relation to this client group. Kellett, Beail and Newman (2005) addressed this problem by administering the scale to 255 participants with learning disabilities. The scale was found to be generally psychometrically sound, thus strengthening earlier conclusions, but the exercise illustrates how the need to adapt measures further undermines the limited data on outcomes.

Prior to this, the few outcomes which were measured had tended to rely upon behavioural observations (Prout & Nowak-Drabik, 2003). Beail did not discount the potential usefulness of behavioural measures. He observed behaviour before and

after short term psychotherapy to chart positive changes in 25 clients with difficulties with aggression (Beail, 1998).

Newman and Beail (2002, 2005) gave evidence for the development of new positive schemas in clients during the process of psychotherapy, which accords with the assimilation model of predicted change. The study used the Assimilation of Problematic Experiences Scale (APES) that describes a systematic sequence of changes, identified by the client's statements and behaviours (Barkam *et al*, 1996). Interestingly, although significant positive change was recorded, clients with learning disabilities entered therapy at a lower stage of assimilation, that of avoidance, than clients without disabilities.

Beail's studies reported on different client groups, as well as using differing outcome measures, including a dual diagnosis client group (Beail & Warden, 1996) and a forensic cohort (Beail, 2001). Both studies provided evidence that psychotherapy could produce significant reductions in psychological symptomology and was associated with significantly reduced rates of recidivism for the latter group.

In all, Beail's studies represent probably the most creative and systematic work in the field of learning disability outcome studies. However, the number of participants are still small, and adaptations to measures largely psychometrically unsubstantiated. In his re-review of the field in 2003, Beail concluded that, measured by the usual standards of empirical evidence, the case for effectiveness was weak, but that conversely, the limited evidence available did provide a positive indicator for psychotherapy.

Willner (2005) agreed with these conclusions, citing the lack of randomised control trials. In contrast, Sturmey (2005) reviewed evidence of different interventions and published his findings under the heading of “Against therapy”. Sturmey claimed that behavioural approaches remained the preferred option for people with learning disabilities.

Sturmey’s (2005) paper is particularly relevant, in that exclusion might be justified by empirical evidence of ineffectiveness. However, a number of flaws were pointed out in both conclusions and methodology of Sturmey’s (2005) work. Beail (2005) noted that the review incorporated data from studies with children and was largely based on participants with severe or profound disabilities in institutional settings. He claimed that the categories used to define presenting problems were ill-defined, and that mental health topographies accounted for only 1.25% of the data upon which Sturmey had based his conclusions.

Hurley (2005) criticised the inclusion of cognitive techniques such as problem solving training under the heading of behavioural interventions, and noted his exclusion of additional reports, including clinical case reports. Taylor (2005) pointed out similar objections.

In all, Sturmey’s (2005) conclusions are not convincing. One difficulty lies in the definition of psychotherapy. Although Sturmey’s (2005) review mentioned one case of “traditional psychotherapy”, it did not distinguish psychodynamic therapy from other forms, including cognitive behavioural therapy. Willner (2005) and Beail (2003) conclude that it is hard to comment with any degree of certainty on the

effectiveness of psychotherapy from the available data, and even less possible for the narrower definition of psychodynamic psychotherapy.

King (2005) condemned the simplistic approach to categorising interventions underlying Sturme's (2005) review, and the methodology does indeed appear too clumsy for the complexities of this client group. Willner (2005) identifies that the evolution of research in this area reflects the paradigm of "practise –based evidence" rather than "evidence-based practise" (Barkham & Mellor-Clark, 2000).

The former paradigm is far better suited to the evidence. In this way, the anecdotal and single case studies that predominate, and are easy to criticise in terms of lack of outcome measures, can be seen as a valuable component of a meta developmental process. Salkovski's (1995) hour glass model postulates a process whereby clinicians identify a problem and begin small scale exploratory investigations. This leads to "purer" research in line with standards for evidence based practise (Chambless *et al*, 1998). This then generates the dissemination of information and it's testing in field conditions.

In all, the state of research is perhaps best summed up by Beail's (2003) observation that the "absence of efficacy is not evidence of ineffectiveness" (p. 471) as the work is only just arriving at the stage in which field testing has been generated. For the purposes of this review, effectiveness does not have to be proven. Rather, there simply needs to be sufficient evidence on which to argue for exclusion. Based n the information available, this conclusion does not appear to be justified.

Despite this, a recent multi-disciplinary survey by the Royal College of Psychiatrists (2005), showed that most respondents still believed that individual psychodynamic psychotherapy was likely to benefit people with learning disabilities less than cognitive-behavioural therapies, family therapy or group work, despite the lack of adequate supporting evidence (Beail, 2005).

It is possible that due to Freud's reservations, practitioners were still merely over cautious in applying techniques in the infancy of psychotherapeutic approaches. It is interesting to compare people with learning disabilities with other groups previously excluded from therapy. Bender (1993) notes that groups excluded included those with psychosis despite the Freud having not ruled out appropriate adaptations in techniques overcoming his original reservations. Bender proposed that the psychotherapeutic institutions set up rules of exclusion for disfavoured groups. It is thus possible that people with learning disabilities were caught up in the exclusory rules by accident, as the prospect of any therapy would have been inconceivable at that time.

However, Bender observed that the rules for some groups have changed. British Psychoanalytic Society, until 1986, excluded patients over 40 years of age. However, it would seem highly unlikely that any therapist would nowadays claim the principles were not applicable for this group, or claim they lacked the skills required to work with these clients. Yet Nagel and Leiper (1999) suggested that 59% of psychologists felt they lacked the competency to work psychoanalytically with this client group.

Why then, should therapists continue to avoid offering services to this group based on apparently insufficient evidence, and question skills which might be adjusted to suit other categories of adult service users? There appears to be a need to explore reasons other than the suitability and effectiveness of the technique to account for the “unoffered chair”

The Social Context

“ Disability is something which can only exist in relation to something else, or someone else and therefore it is not only a problem for one person or another, but also a problem of discourse. In other words, the location of the disability could be said to be between people rather than in people.”

(Bungener & McCormack, 1994, p. 365-366)

Bungener and McCormack (1994) identify here the key notion that learning disabilities are not *intrapersonal*, but *interpersonal*. Thus this group is actually defined by their social identity, and need to be considered in this context. The authors assert that the “adhesive identification” (p. 371) we use to make links with others, is faced with overwhelming “differentness” in individuals with learning disabilities, leading to the building of stereotypes.

Goffman (1963) explored the concept of stigma, a “spoiled identity”, or global attribution of the self as failing to reach the individual’s cultural standards. Lewis (1998) described stigma thus:

“The whole self becomes defined by the stigma. The expressions “the Down’s child”, the mentally retarded person,” or “the fat lady” all reflect an inescapable realization that the stigma is the defining feature of the self.”
(p. 128)

Wolfensberger’s (1972) famous treatise identified that those with learning disabilities are characterised as “man as other”, because of their level of perceived difference. The negative impact of this stigmatising collective identity can be seen throughout the history of people with learning disabilities, from the Eugenics movement, through Nazi extermination policies and the setting up of Asylums (Ryan & Thomas, 1980).

This does suggest that in addition to any theoretical rationale about the inability to make use of therapy there must run a parallel social process, which perhaps identifies this group as neither worthy of such input, nor sufficiently “human” as to experience a similar psychological life to others (Ryan & Thomas, 1980).

Hardly surprising, then, that this stigmatised identity has had an impact upon the way that services and clinicians approached the group. Wolfensberger (1972) highlighted the exclusion of this group from mainstream society, including health services. Hughes (1945) described having a learning disability as a “master status” which superseded all other social identities. Phillips (1966) noted that signs of psychological distress were often misdiagnosed as corollaries to learning disability rather than seen as a separate issue, and therefore went untreated.

The term “diagnostic overshadowing” was coined by Reiss *et al* (1982), whose studies showed that being identified as having a learning disability reduced the likelihood of being given another, mental health related diagnosis (Reiss & Szysko, 1983). Bender (1992) argued that the development of specialised services tacitly institutionalised overshadowing. He claimed that the evidence showed how being part of a stigmatised group has a major impact upon the services offered to that particular cohort. This begs the question of how social identity might affect the decisions of individual clinicians, faced with the treatment of stigmatised individuals.

Goffman (1963) described “courtesy stigma” by which those associated with a stigmatised individual might be infected. Studies have shown that having a learning disabled child stigmatises the parents (Rimmerman, & Portowitz, 1987) and Schelles (1999) describes similar distress in siblings.

Ogle’s (1963) comments suggest that it may also apply to professionals, speaking of “group embarrassment” in relation to working therapeutically with people with learning disabilities. Limited reference to this phenomenon can be found in the literature of the field. Mitchell (2000) explores a stigmatising process for nurses working with those with learning disabilities which parallels the experiences of their clients.

In the recent report from the Royal College of Psychiatrists (2005), whilst the lack of input was blamed mostly on resources, prejudice and unhelpful perceptions about people with learning disabilities were cited as barriers to service provision. The report does not identify whose prejudices these might be (or indeed to whom they

may be directed) although an earlier survey of psychiatrists had shown learning disabilities to be the least preferred speciality (Hook, 1973). Hollins (2000) reported a survey indicating that most junior doctors chose alternative specialities. Those that chose to work in the field of learning disabilities did so only after experiencing a positive placement, or because they had a family member with a learning disability.

Professional avoidance is not confined to psychodynamic practitioners. Sternfoert Kroese (1997) reports from the field of cognitive-behaviour therapy that:

“ ...although the pure Skinnerian ‘black box’ approach to cognitive processes has been rejected by most and people with learning disabilities are now credited with thought (be it verbal or non-verbal), cognitive – behaviour therapists have so far failed to show any great interest in welcoming these clients into their clinical practises.” (p. 6)

The neglect of this client group has been perpetuated by educational structures. Only in the last three decades have psychotherapy trainees been able to have clients with learning disabilities as training cases, following the lead of Joan Symington (Sinason, 1992).

Simpson (2004) offered an explanation suggesting that:

“There can be an unconscious aversion amongst people training as psychotherapists and counsellors to taking on patients with learning disabilities. This can be based on a fear that is, in part, socially conditioned.” (p. xxiii)

Evidence suggests that factors of social identity may be impacting on professionals' decision making processes. Retzinger (1998) proposed a concept of ideological counter transference which may link social influences with the therapist's response to his or her clients. However, before exploring this further, it may be useful to define the meaning of counter transference.

Transference and Counter Transference

Freud (1910) first described the processes of transference and counter transference in the therapeutic relationship. Transference is seen as conscious and unconscious responses from a client towards an other. LaPlanche (1988) defines transference as;

“...a process of actualisation of unconscious wishes. Transference uses specific objects and operates in the framework of a specific relationship established with these objects. (p. 455)

LaPlanche notes that by some definitions, transference connotes all the phenomena which constitute the client's relationship with the therapist. Complimentarily, counter transference is the term for the equivalent feelings evoked in the therapist by the client:

“The whole of the analyst's unconscious reactions to the individual analysand – especially to the analysand's own transference.” (LaPlanche, 1988, p. 92)

In classic psychoanalysis, counter transference was interpreted from an epiphenomenalistic standpoint, as a negative side-effect of therapy which reflected the therapists' own unresolved personal conflicts. In most research studies, the interpersonal relationship between client and therapist, necessarily incorporating the concept of counter transference, has been shown to be a key factor in deciding outcome, regardless of model (Henry, 1998; Orlinsky & Howard, 1986).

In modern psychoanalysis, counter transference is now considered a valuable process of information gathering in psychodynamic approaches, providing a means by which the client's experiences may be understood.

Retzinger's (1998) ideological counter transference relates to a "third party" in the therapeutic relationship, and may take the form of theoretical perspectives, belief systems or clinical positions. It acts to interfere with the direct reciprocal relationship with the client. In particular, it allows the therapist to locate the "problem" in the client, which Retzinger believed leads to discrimination or projection.

Ideological counter transference would thus encompass both the belief that clients with learning disabilities are cognitively unable to make use of therapy, but also beliefs based on the roles and stereotypes that Goffman (1963) and Wolfensberger (1972) describe. Of course, prescribed roles are not exclusive to people with learning disabilities. Orlinsky (1986) describes considerable research into role investment in mainstream therapy. However, the roles assigned to people with learning disabilities are particularly negative.

Wolfensberger (1972) proposes that people with learning disabilities, too, are aware of the role that has been projected onto them and may therefore perpetuate ideological counter transference through their actions:

“When a person is perceived as a deviant, he is cast into a role that carries with it powerful expectancies. Strangely enough these expectancies not only take hold of the mind of the perceiver, but of the perceived person as well.”
(p. 15)

The belief that people with learning disabilities have an awareness of the roles projected onto them is inherent in the concept of secondary handicap described earlier. Case examples are given of where clients present themselves in accordance with Wolfensberger’s (1972) stereotypes of; “menace”, “object of unspeakable dread”, “eternal child”, “diseased organism”, (p20-23) and more (Sinason, 1992; Stokes, 1987; Symington, 1981; Korfe-Sausse, 1999; Parsons & Upton, 1986).

Empirical evidence of role adoption does not appear to have been explored, but awareness of a stigmatised identity is supported in the literature. Szivos-Bach’s (1993) findings showed that young people who perceived themselves to be most stigmatised had the lowest self esteem and felt least likely to fulfil their aspirations. Jahoda’s (1988) study found similar awareness.

Spoiled Identities and the Therapeutic Relationship

Thus the awareness of the social context may impact on both the therapist and client.

One can ask whether other elements specific to individual therapeutic relationships with people with learning disabilities may be challenging to the professional.

Lopez (1974) highlights the unpopularity of engaging therapeutically with children with impaired intelligence. As he says:

“Therapeutic efforts in which a prolonged and intimate relationship between child and therapist is central, are, to judge from the literature, extremely rare ...” (p. 278)

Sternfert-Kroese (1997) noted that, regardless of therapeutic speciality, true working alliances were rare and difficult. There is some evidence to suggest that carers and professionals may avoid emotional identification with such clients. One study asked both clients and their attendant carers and professionals about the clients' responses to bereavement (Harper & Wadsworth, 1993). Results showed that clients spoke primarily in terms of emotions whilst professionals and carers predominantly described behaviours.

Symington (1981) muses about the responses evoked by people with learning disabilities. He relates this to the proffering of psychotherapeutic services:

“I think there may be another reason that deters us from treating people who are subnormal. It is that we are all retarded in some areas of our

mental functioning. One of us says, "I am absolutely useless at maths," another says, "I can never understand a word of philosophy," and another, "I can never understand a word of economics," and so on. When we treat a subnormal patient we are reminded only too poignantly of our own mental retardation. It is only too understandable that we prefer not to be so reminded." (p. 199)

Hodges (2003) summarises the process of projection to which Symington alludes. She claims that society projects feelings of inadequacy, disability, ugliness and insecurity into people with learning disabilities. What Goffman (1963) describes as a social process, is translated into personal experiences and defences.

Some writers have clearly postulated that learning disabled clients may evoke uncomfortable counter transference within therapists (Alvarez & Reid, 1999, Ryan & Thomas, 1984). Negative transference describes the situation whereby unpleasant feelings such as hostility and rejection are evoked within a relationship. Whilst addressing these feelings is an expected and necessary part of the therapeutic work, Storr (1979) points out the destructive potential of failing so to do.

"In cases where negative transference cannot be resolved, therapy will come to an end because the patient will break it off. (The same may be true in the less common reverse case, in which the therapist has a negative counter-transference toward the patient which cannot be resolved)." (p. 73)

The available literature suggests that this may not in fact, be less common where clients with learning disabilities are concerned. Mannoni (1973) describes similar instances where therapy with clients with learning disabilities is terminated through what she considers to be unresolved negative transference. It was reported that the psychiatrists who did not favour work with people with learning disabilities (Hook, 1972) identified transference and counter transference as the most important elements in their experience of training, begging the question of whether negative transferences are anticipated.

It is unclear whether prospective therapists might be concerned about encountering the “real” (Schneider, 1999) issues that people with learning disabilities face. Sinason (1992) emphasises the traumatic nature of working with this process, as she says;

“Where death, damage, torture, decay, chromosomal abnormality and organic malfunction are alive in the session the therapist has the task of facing the real hurt...” (p.81)

Hollins and Sinason (2000) have recently equated the trauma of learning disabilities to the definition given by the American Psychiatric Association (1994). There are difficulties with the parallel, in that the definition requires “suddenness” as an expected part of trauma. This might apply to the shock of diagnosis of learning disability or the traumatic experiences a person might be prone to as a result of their learning disability. Whilst the identification is not complete, this opens up parallels for the therapist to the experience of “vicarious trauma” (Pearlman & Saakvitne, 1995).

In what might be described as “chronic” trauma, Hollins and Grimer (1988) described three “secrets” which characterise work with people with learning disabilities. They proposed that these were the disability itself, sexuality and death.

With regard to the disability itself, the authors identify the grief associated with the loss of the perfect child or self, which the family and individual experiences. This grief is remarked on by most writers in the field and can continue over a lifetime (Bicknell, 1983, Sinason, 1992). Hollins (1992) makes reference to the impact this may have upon the therapist claiming it is appropriate for the therapist to be able to share the reality of the disability: to be able to feel the hopelessness of the situation and a sense of disappointment or even panic. This sense of distress in addressing disability has been described in other cases (Hodges & Sheppard, 2004; Jones & Bonnar, 1996)

Mannoni (1973) illustrated one way in which primary handicap impacted upon the therapist. She noted the very real dependence issues for her clients, that meant parents often could not be kept separate from the therapeutic process. She recognised the need to listen to the parents’ viewpoints as an aid to formulation. Mannoni theorised that the consequence of this was that therapists were pushed towards identifying with the issues of the mother, rather than of the client. Jones and Bonnar (1996) endorsed this by reporting marked maternal counter transference in their experience of running group therapy.

Mannoni (1973) believed that maternal counter transferences with clients with learning disabilities would not be comfortable for the therapist. She postulated that murderous feelings are present in the relationship of mother and the child with a disability, even if those feelings are disguised or denied.

This accords with Hollins and Grimer's (1988) assertion that the secret of "death" is inextricably linked with parental relationships. This is claimed to be both a fear of losing parents upon whom they are dependent, but also fear of individual's own mortality, in recognition of the parents' murderous feeling towards their imperfect offspring. Sinason (1992) described cases where clients' demonstrated their emotional awareness of the destructive wishes of others towards them because of their disabilities.

Mannoni believed that these powerful emotions would play out in the transference. She observed that the apparent lack of cognitive ability on behalf of the client resulted in the "complete non-satisfaction" or "boredom" (p52) of the therapist. She noted that therapy was often terminated by the therapist who felt nothing more could be achieved. Other theorists (Sinason, 1992, Reyes-Simpson, 2004, Hodges, 2003) have noticed overwhelming lethargy, or the slow passage of time during therapeutic sessions. Mannoni framed these phenomena as unrecognised counter transference. The termination of therapy might then be interpreted as a symbolic expression of this wish for the imperfect and "unsatisfying" client to be therapeutically dead.

The last of Hollins and Grimer's (1988) secrets is that of sex; the taboo of sexuality and people with learning disabilities. The prevalence of sexual abuse in this client

group (Turk & Brown, 1992) means that therapists have a strong chance of being faced with the impact of sexuality and abuse in their contact. Disclosures or therapists' concerns about abuse are frequently reported in case studies (Sinason, 1992; Emmanuel, 2004). Corbett *et al* (1996) describe the traumatic effect acknowledging the abuse histories of clients can have on workers.

The expression of sexuality in clients is often described in the literature as shocking. Sinason (1992) described that in fourteen years of working as a therapist, only two women were able to speak about, or symbolically represent their body's sexuality. The others acted out issues by presenting them physically. Hodges (2003) also described cases whereby clients displayed their vagina or masturbated in the sessions.

As is apparent from the examples above, not only were specific, powerful transferences and key issues likely to arise with this client group, but the therapist was also faced with completely atypical ways of communicating meaning. Parsons and Upton (1986), in their survey on experiences of therapists from the Tavistock clinic, noted that without exception, clients presented with behaviours not routinely seen from mainstream attendees.

Therapists were faced with behaviours that broke the conventions of therapy. These included; intense questioning, inappropriate demands, arriving early or late for appointments (Parsons & Upton, 1986). Other authors confirm similar experiences of clients' domination of the sessions (Symington, 1981). Kakogianni (2004) described how one client who would climb on the windowsill in the therapy room.

In contrast, reports also include extreme passivity or non-engagement with the therapeutic process. Clients were described who did not seem to engage in genuine contact with the therapist (Kauffe-Sausse, 1999) or presented with submissive behaviours which impeded the process (Sinason, 1992). Sinason identified what she described as the “handicapped smile”, intended to placate a more powerful other.

Presentation often took the form of “acting out” (Perry, 1990). Perry defined acting out as an episode whereby:

“The individual deals with emotional conflicts, or internal or external stressors, by acting without reflection or apparent regard for negative consequences. Acting out involves the expression of feelings, wishes or impulses in uncontrolled behaviour with apparent disregard for personal or social consequences. It usually occurs in response to interpersonal events with significant people in the subject’s life, such as parents, authority figures, friends or lovers.”

Examples of acting out experienced in sessions included behaviour as extreme as setting fires (Parsons & Upton, 1986). Physical or verbal assaults on therapists were described (Baikie, 2004; Ruth, 1999; Hodges & Sheppard, 2004). Self harm such as scratching, eye gouging, spitting and smearing has been observed (Hodges, 2003, Sinason, 1992).

These atypical behaviours presented major challenges to therapists working with this client group. Stokes (1989) and others identified the difficulty inherent in separating organic damage which genuinely affects an individual’s capacity from the

psychological limitations later imposed, i.e. determining whether a client's presentation is due to primary (organic) limitations, or due to secondary (psychological) handicapping. (Simpson, 2004; Lee & Nashat, 2004). In addition, the therapist still has to respond to a situation which is outside the boundaries of usual social interactions.

In particular, the phenomenon of opportunistic handicap promises to evoke difficult emotions in the therapist. Jones and Bonnar (1994) noted that social awareness was shown by the members of their therapeutic group who doubted their acceptability to others, and expressed envy of others' relationships. Envious attacks towards therapists are noted in the literature. Stokes (1987) described how one client would habitually ask unanswerable questions that made the therapist feel as if they were the "stupid" one, a counter transference frequently described in the literature (Sinason, 1992; Hodges, 2003; Hodges & Sheppard, 2004)

As Stokes describes:

"In my view he was doing this to reverse the tables, to have me as the one who was helpless and could not understand things. But in addition I felt it also had an aggressive, envious quality, envious that is of my capacities which he was implicitly mocking." (p.4)

Stokes went on to reflect that there may be a significant degree of fear of the level of envy that could be directed at a non-disabled therapist and identified the additional uncomfortable feeling of guilt which could be evoked in response.

Discussion

A review of the literature on the topic of the nature of psychotherapeutic relationships based on psychodynamic principles with people with learning disabilities faces a number of difficulties. Firstly, there is very little information available due to the application of the approach being in its infancy. What information there is proved difficult to access. Searches of major psychological data bases revealed no results associated with key words of “learning disabil”, “mental handicap”, “psychotherapist” and “transference”. The limited references which emerged from searches which included “psychotherapy” covered a wide range of interventions.

There are generic difficulties in empirical data relating to people with learning disabilities. Difficulties in categorisation are apparent in the attempts to review the literature from different interventions. Sturmey’s (2005) review demonstrated how amorphous the label of “psychotherapy” can be. There are particular problems in identifying or reconstructing categories of presenting problem for this client group. The observations made by Hughes (1945) and Phillips (1966) also seem relevant when considering the literature; for instance, the criticisms level at Sturmey (2005) for failure to distinguish mental health categories adequately may reflect the master identity of learning disabilities through which psychological distress is missed. Beail (2005) notes how outcomes can then be misinterpreted according to how the researcher constructs the behaviour in the first instance.

The difficulties in categorisation also apply to the client group themselves. The severity of learning disabilities is not distinguished in some reviews. When attempting to review literature on support for people with multiple and profound

disabilities, Nakken and Vlaskamp (2002) found twelve different descriptions pertaining to the group out of the thirty five articles.

There is a problem here in that people with learning disabilities are treated as a homogenous group for the purposes of providing services and research. However, this categorisation is based on functioning, rather than any unifying theory. Even using a biomedical model, this group is not homogenous.

However, despite differing orientations, clinicians seem agreed that organic disabilities do exist. If undifferentiated, the conclusions drawn about therapeutic approaches may be based on unrecognised uncontrolled variables relating to the individual's abilities. Yet even where this differentiation is made, the difficulty of distinguishing between primary and secondary handicaps has been noted and psychogenic learning disabilities proposed.

The limited amount of information on this topic means that much of the information from studies with adults is compounded with that of children. This difficulty is not confined to outcome reviews. Much of the case study material relates to therapy undertaken with children (Sinason, 1992; Kaggianni, 2004; Emmanuel, 2004). It is dangerous then to extrapolate this to work with adults. Features described as significant in the therapy, such as boundary breaking may be due to developmental immaturity rather than the learning disability.

Whilst the contributions from the small number of authors publishing anecdotal case studies have been immensely useful as a valuable part of the practise –based evidence

paradigm, the field tends to suffer from what might be described as “epistemological incest”. Almost all material is drawn from the work of those associated with a handful of key theorists and clinicians. For instance, one of the two collections of case studies, which represents the richest pool of recent evidence is generated by clinicians from the Tavistock Centre (Simpson & Miller, 2004), whilst the other, edited by De Groef, features a chapter by Sinason (1999). Thus new work tends to use the same frame of reference and significant challenges to theories are absent from the literature.

Challenges are not made to the specific psychotherapeutic theory itself, in relation to people with learning disabilities. Information and research from other conceptual frameworks relating to people with learning disabilities are not triangulated with the interpretations. For instance, the research on “theory of mind” (Frith & Happe, 1999) suggests limitations as to insight of others’ perceptions. This would appear to be important with regard to Sinason’s (1992) assertions of clients’ awareness of the negative impulses of others towards those with disabilities.

Further Research

Clearly further research is required. Given the significant role played by individual practitioners in determining whether people are offered psychotherapy (Royal College of Psychiatry, 2005), an appropriate focus of attention may be the attitudes of therapists towards this client group. An exploration of whether therapists hold expectations of specific negative transference would be particularly valuable.

A major area of lack is that of information regarding the therapeutic process. The perspective of therapists working with this client group is almost wholly unexplored. Information is only available inferentially, as no direct work has been done on the therapist's experience of therapy. Investigation into the nature of this work would be valuable in exploring the impact of this client group on the therapist, and the ways in which negative transferences are experienced and managed.

It would be valuable to explore outcome options for case descriptions which have previously relied upon clinicians' judgements as to outcomes. It would be interesting to explore whether projective tests could be combined with other outcome measures to provide reliability and validity checks to determine the value of pursue this form of measure.

With regard to the effectiveness of psychotherapy, larger scale outcome studies would be more valuable than attempting to collate information from different studies. In an attempt to produce a stronger evidence base, Willner (2005) recommends the use of randomised control trials. However, there are arguments regarding both the appropriateness and practical applicability of this form of enquiry.

Firstly, one could argue that the field is insufficiently advanced for this type of enquiry to be useful, that it is still in the "practise-based evidence" phase of Salkovski's (1995) model. Others, such as McLeod (2000) would argue that qualitative methodology is much better suited to the subtleties of research into psychotherapy.

The pragmatic difficulties would be significant. The evidence cited previously notes the complexity of the learning disability categorisation. Concepts such as emotional intelligence would make matching difficult, as equivalent IQ scores could not be assumed to indicate similar levels of ability with regard to insight or psychological mindedness. Psychogenic learning disabilities may be indistinguishable from organic limitations but may be hugely influential on outcomes. Even where organic causes are clearly present, Arvio and Sillanpaa (2003) found 61 different syndromes, with varying impact of the individuals' functioning, within a population of 461.

One difficulty with the RCT methodology is the complexity of contextual elements of peoples' lives. Simplistic distinctions such as institutional versus community settings may not capture significant variables. The standardisation of the treatment package to be evaluated is equally problematic. The preceding literature cites how psychodynamic principles need to be adapted to the individual, with resulting in potentially larger variations in medium, setting and boundaries than one would find in an equivalent mainstream study.

Finally, Gates and Atherton (2001) note that effectiveness is not the only factor that should apply to interventions in health and social care. They state that for people with learning disabilities, equity, appropriateness and accessibility are important factors, a position which places the scientific within the context of the social, echoing the dual strands of this review.

Conclusions

In considering Bender's (1993) proposition that the reasons for excluding people with learning disabilities from psychotherapy are prejudicial rather than empirical, the literature does offer support for his assertion. Rather than having to prove the case for inclusion, surely the onus should be providing sufficient grounds to justify excluding part of the population.

The theoretical basis for exclusion due to intelligence can clearly be questioned. There is research to argue that intelligence is not a unidimensional concept. The concept of loss of intelligence as a defence is illustrated in case studies and acknowledged by Freud (1920) himself. The concerns regarding intelligence are, however, conceptual objections. Even if there were no evidence to the contrary, exclusion could not be logically justified until the proposal was empirically proven.

The empirical evidence available is agreed to be an insufficient for conclusions to be drawn as to the effectiveness of the approach for this population. Early indications are that the approach can be effective, but again, proof of effectiveness is not required to question the validity of exclusion.

What information exists does not necessarily address the issues of the therapeutic relationship. Rather, emphasis is often on technique or outcome due to the needs of the emerging field.

Bender's (1993) suggestion of exclusion being prejudicial appears well founded.

There is evidence to suggest that the social identity of people with learning

disabilities impacts on clinicians' decisions. At a collective level, the "spoiled identity" of learning disabilities may have encouraged the belief that the approach would not be suitable.

Retzinger's (1998) concept of ideological counter transference offers a bridge between the collective, social processes described by Goffman (1963) and Wolfensberger (1972) and the individual's experiences and defences. For this counter transference to be significant in the decision to avoid offering therapy, it would need to have an anticipatory component. Whilst this is not mentioned specifically, the nature of the phenomenon she describes clearly incorporates beliefs and emotions external to the immediate therapeutic situation.

The actual experience of psychotherapy with clients with learning disabilities is only derived through extrapolation from case accounts. However, it appears engagement with the real issues of learning disabled clients brings serious challenges for the therapist. The traumatic nature of the disability may well have an impact upon the therapist, as working with other traumatised groups is known to do. (Pearlman & Saakvitne, 1995). The therapist may have to cope with atypical behaviours. In particular, the dynamic of able therapist and disabled client may leave the therapist open to envious attack, feeling helpless and inadequate, the very experiences Symington (1981) proposes we wish to avoid.

It is significant that Hollins (2000) describes how junior doctors are drawn into the field only after experience with the client group. This perhaps suggests that, difficult though these issues are, people find it is possible to work with the negative

transference. It is perhaps ultimately an expectation of negative transference which may inhibit individual clinicians from offering services.

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Part Two: Research Report

Therapists' Experience of Learning Disabled Clients

Key words: Learning disabilities, psychodynamic psychotherapy, IPA

Abstract

Background: Little is known about the experience of the therapeutic relationship with clients with learning disabilities. This study aimed to explore individual practitioners' experiences, including those of transference and counter transference with this client group.

Materials and Method: A semi structured interview was used to elicit personal accounts from eleven therapists working psychodynamically with clients with learning disabilities. Data were analysed using the principles of Interpretative Phenomenological Analysis (IPA) to produce relevant themes.

Results: Two super-ordinate themes emerged, one identifying similarities and differences from work with other client groups, the other noting the issues impacting on the therapist from working with the "spoiled identity" of a learning disability.

Conclusions: The findings accorded with previous clinical reports. Theoretical links were made with the fields of psychodynamic psychotherapy and shame research.

Implication for clinical settings and future research were discussed.

Background

The offering of psychotherapy to people with learning disabilities is a recent phenomenon, after a long history of therapeutic disdain (Bender, 1993). As yet, little is known about what the experience of therapy is like for those clinicians who take an inclusive stance. Of necessity, the early literature in the field initially focussed on demonstrating the ability of cognitively impaired clients to engage with therapy (Symington, 1981; Frankish, 1982; Sinason, 1986, 1992). As access to therapy services began to be extended, research emerged on adapting and disseminating therapeutic techniques (Hodges, 2003; Conboy-Hill, 1992) and investigating these techniques' effectiveness with this population, through systematic outcome studies (Beail, 1995, 1998, 2001, 2003, 2004; Beail & Warden, 1996; Beail; Newman & Beail, 2005).

However, despite the recognised importance of the therapeutic relationship in the outcome of therapy, and numerous studies on the issue with clients without disabilities (Orlinsky *et al*, 1994) little is known about the nature of the therapeutic relationship with learning disabled clients. Mannoni (1973) described the work as distinct from that with clients without disabilities. Hollins and Grimer (1988) postulated that therapists would be faced with specific issues with this client group, describing three defining "secrets" including; the disability itself, sex and death. Frankish (1989) explored the impact of the primary disability on the personality and Stokes (1987) and Sinason (1986) introduced the concept of *secondary handicap* to explain how limitations were exaggerated as a defence against trauma and used opportunistically to express anger and envy.

The means by which these meanings are communicated are atypical of non-disabled clients. Clients might direct aggression towards others or themselves (Ruth, 1999; Hodges & Sheppard, 2004; Hodges, 2003). Dominance, passivity, boundary breaking and sexualised behaviour have all been noted (Korf-Sausse, 1999; Symington, 1981, Sinason, 1992).

Modern psychodynamic psychotherapy describes transference as a primary means by which the therapist experiences their client. Negative transference, where uncomfortable feelings are evoked within a relationship, is described as rare by Storr (1979), but is frequently described in the literature for people with learning disabilities (Alvarez & Reid, 1999, Ryan & Thomas, 1984). Specific counter transferences reported as part of case descriptions include feelings of stupidity, interpreted as envious attacks from clients (Stokes, 1987). Shock and disgust were described by Sinason (1988) as responses to her clients' traumatic presentation.

Although a flavour of the experience of working with this client group can be extrapolated from case descriptions, systematic research into therapists' experiences is missing from the literature. Thus, this appeared to be a valuable area to begin exploring in this study.

Qualitative methodology was selected as being best suited to providing rich data on this subject, as well fulfilling a heuristic role of generating questions which might be addressed using quantitative methodology.

McLeod (2000) reviewed the contribution of qualitative research to the evidence base for psychotherapy and concluded that qualitative research could be very valuable in contributing to an increased understanding of psychotherapy. McKenna and Todd's (1997) study, in which clients described different kinds of therapeutic experiences, noted that the subtleties of the process would not have been identified by quantitative methodology. Qualitative methodology is held to be valuable where exploration of a field of interest has only just begun, and a broad rather than narrow focus for investigation is required (Marshall & Rossman, 1995). Smith (1995) claimed that semi-structured interviews and qualitative analysis were especially suitable where one is particularly interested in complexity or process, or where an issue is controversial or personal.

Within the qualitative approaches, a number of possible methodologies exist. In depth comparisons are beyond the scope of this report but the applicability of the different models to the current study is considered. Discourse, conversational and narrative analysis have been criticised for their relativistic slant (Rennie, 1999). The focus is placed on deconstructing the narrative as behaviour, which is not the primary interest of this study. Grounded theory (Glaser & Strauss, 1967) aims to construct a theoretical model from participants' data. However, the current study is intended to cover the unexplored primary issues and experience of individuals working with people with learning disabilities. Therefore, grounded theory methodology might most usefully be employed at the next stage of exploration.

Interpretive Phenomenological Analysis or IPA, (Smith, 1995) was selected as the most appropriate methodology for this study due to the focus on the participants'

inner world. IPA is designed to attempt to explore peoples' lived experiences, and the sense they make of these experiences. The approach aims to investigate the meaning of events or states rather than claim to define these events or states objectively. This approach, in particular, seemed congruent with the subject matter with its emphasis on the interpretative. As with other qualitative methodologies, IPA incorporates thematic analysis but aims for further depth, of analysing the meaning of themes rather than simply placing text into descriptive categories. The interpretative element also explicitly acknowledges the "double hermeneutic" status of this kind of inquiry. It recognises and utilises the questioner as part of the process.

Method

Eleven professionals who offer psychodynamic psychotherapy to clients with learning disabilities were invited to give personal accounts of their work. Following ethical approval, a semi-structured interview, constructed using the principles identified by Smith and Osborn (2003), was undertaken with the participants. A descriptive thematic analysis (IPA) was then applied to the transcripts.

Materials

The interview schedule was developed through Smith and Osborn's (2003) process outline of four stages, which were used to generate the interview questions. The broad range of topics related to therapists' experiences were identified and arranged in a logical sequence. Open, non-leading questions were then identified and secondary prompt questions generated. The appropriateness of the schedule and research protocol was then checked in consultation with a service user representative.

Procedure

Potential participants were recruited from the membership lists of the Institute of Psychotherapy and Disability (IPD). The IPD is an organisation which fosters the practise of, and research in, psychodynamic psychotherapy with clients with learning disabilities. This source was chosen as eligibility for membership met stringent academic and experiential criteria, ensuring appropriate purposive sampling.

Membership required that:

- Participants had a post graduate degree in psychotherapy, or an equivalent professional qualification.
- Participants had a minimum of two years experience of working in a psychodynamic model with people with learning disabilities.
- Participants had worked with a minimum of ten clients, including two cases with therapy extended over a minimum of one year.

A letter of introduction was sent to the Chairperson of the IDP asking permission to contact members. When this was received, all members of the IDP were sent information regarding the project. Twenty members responded and each was then contacted by the researcher to discuss participation. Of those who responded, eight were not interviewed due to geographical location, non-dynamic therapeutic orientation and not yet having reached the criteria for full membership of the IPD. A further participant was unable to be interviewed within the data collection period.

The remaining participants were given information which included an explanation of the interview process, data collection and storage. Anonymity was guaranteed for both them and any clients described. Limits of confidentiality were also described, including the need to act on any malpractice disclosed. Consent was obtained at this

stage, and checked again prior to interview. Participants chose when and where the interviews were to take place.

Participants were asked if they would be willing to be part of a sample contacted by telephone or email after their interviews had been analysed, in order to check the fit between the researcher's emergent themes, and the participant's experience.

Participants were also offered the opportunity to receive feedback on the completed study.

Participants

The purposive sample consisted of eleven participants, six women and five men.

Participants' ages ranged from 36 to 58 years. All participants were White. All were currently actively involved in working therapeutically with clients with learning disabilities. The settings in which participants worked included educational establishments, social, forensic and health care services, and voluntary institutions. The ages of clients ranged from those in secondary education to older adults. The sample's professional backgrounds encompassed social work, teaching, medicine, creative therapy and psychology.

Data Collection

Interviews took place in venues chosen for convenience by the participant. Sites included day services, university offices and participants' homes. Where interviews were held off campus, safety procedures were set in place.

The interviews ranged from between forty to one hundred and twenty minutes long. Interviews were recorded using audio tape for later transcription. The interviews were conducted in accordance with Smith and Osborn's (2003) recommendations, using the prepared schedule to elicit experiences but attending to establishing rapport, using minimal prompts, being flexible as to the structure of the questioning and monitoring the effect of the interview upon the respondent. Immediately after the interview, the researcher recorded her impressions and thoughts on the process in a field diary for cross referencing with the data produced by the participant.

Data Analysis

Interviews were transcribed verbatim and the data analysed using the method identified by Smith *et al* (1995):

1. The first transcript was read through twice, and read again in conjunction with the tape recording to check for textual inaccuracies and to pick up additional elements of inflection or meaning. On reading through, the researcher's initial observations were recorded line by line in the right hand margin. Observations included summaries of comments, questions and preliminary themes (See Appendix F.ii).
2. Next, emergent themes characterising each section of text were identified and noted in the left hand margin. Clusters of themes were then collected into master themes that reflected the participant's experience (See Appendix F.iv.). This was repeated for each transcript. A summary table of master and sub themes (with their references) was then produced (See Appendix F., Figs. 10. & 11.)
3. Each individual's themes were then compared with the others to produce a summary diagram of super-ordinate themes which characterised the collective

experiences of participants. To aid this process, transcripts were colour coded and text visually displayed in thematic groupings to show significance across cases and keep concepts grounded in text (See Appendix F.vii.).

4. New data emerging with later transcripts were compared with previously identified themes.

5. Analysis continued until all major, relevant themes had been identified.

Quality Control Procedures

Morrow (2005) identified the need to adequately manage the subjectivity inherent in qualitative approaches. A number of quality control measures were adopted to address key areas. These included;

- *Dependability*: this was addressed by making the process as explicit and repeatable as possible, with examples of data at each stage being given in Appendix F.
- *Appropriate Representation of Participants' Data*: checks were undertaken with two participants. These participants were provided with the initial analysis of their interviews and invited to comment. Both reported the analyses to be reasonable representations. Data from their additional comments were incorporated into the body of the report (See Appendix F.v). As an additional check, the first transcript was co-rated by a second analyst for representational validity (See Appendix F.iii.).
- *Rigorous Subjectivity*: One of the key features of IPA is the recognition that the research exercise is a dynamic process (Smith *et al*, 1999). There is an explicit expectation that the researcher needs to be a self-aware contributor to the process. Therefore the researcher kept ongoing notes were in a reflective field diary (See Appendix F.i). The need to make explicit the researcher's own views and biases is addressed in the position statement included here.

Researcher

The researcher was a forty five year old white woman. A clinical psychologist by profession, she had worked for sixteen years in services for adults with learning disabilities. An interest in psychotherapy with this client group was generated by clinical experience and pursued with further training on psychodynamic approaches with people with learning disabilities. A particular interest in research on shame was generated from previous academic pursuits.

Results

The findings of the data collection and analysis process are described in this results section with illustrative quotes from the interviews. The following transcript conventions are used:

... Pause.

— Emphasis given by interviewee.

[] Indicates the removal of irrelevant text or the description of textual content to ensure anonymity.

Participants are referred to by pseudonyms and other names in the text have been changed except where references are made to a contributor to the field. References to text include the participant's name or initial, plus the line reference. Whilst the term "learning disability" is used in reference to clients, "handicap" is used where this is relevant to relate to pre-existing theoretical and linguistic frameworks.

Overview

Following the analytic process, eight master themes emerged from the data. These themes were then grouped into two super-ordinate themes which appeared to reflect commonalities (See Fig.1.). The Super-ordinate theme of “Similarities and Differences” collected comparative observations from participants, whereby their experiences of therapy with this group were interpreted in the light of their experience of therapy with clients without learning disabilities. “Working with Spoiled Identities” was identified as a second theme. Whilst this clearly related to the previous theme, the emphasis here was on the impact on the therapists themselves in dealing with the issues raised within sessions, and the broader context of being a therapist who worked with people with learning disabilities.

Figure 1. Overview of Super-Ordinate and Master Themes

SUPER-ORDINATE THEMES			
SIMILARITIES AN DIFFERENCES		WORKING WITH SPOILED IDENTITIES	
Master Themes			
1.1	Common Ground	2.1	Evolution as Therapist
1.2	Specific Issues	2.2	Impact on Therapist
1.3	Self as Medium	2.3	Courtesy Stigma
1.4	Adaptations to Therapy		
1.5	Primary, Secondary and Tertiary Handicap		

Super-Ordinate Theme 1: Similarities and Differences

The category was made up of five master themes described below;

Common Ground (Theme 1.1): Participants described similarities in working with people with learning disabilities and those without disabilities. At a conceptual level, participants identified a continuum model which highlighted the artificiality of segregating people with learning disabilities. Similar issues arose for client and therapist:

Louise: There was two, if you like, two extremes of the spectrum IQ but it had just seemed the same stuff, there was abuse, trauma and self harm and eating disorders, depression. (L. 468)

Denny: It wasn't any different to my first client I'd seen in mainstream adolescent unit [] just the anxieties about getting it wrong, would I remember everything they'd told me, would I be able to think in the room. (D. 91)

Accounts highlighted alternative forms of intelligence, which equalled those of clients without disabilities:

Alistair: We all know that people who have limited intellectual abilities have sometimes incredibly you know, erm, erm powerful [] emotional intelligence. (A. 315)

Participants reflected that the principles of therapy were universal:

Paul: *I think that all sorts of models from learning disability are equally applicable to any client disorder (P. 378)*

Louise: *In a way we are all working in a field of disability because we are all trying to bring a sort of understanding to somebody else's experience so its not that different and yes, it's a different degree but actually it's what we're all doing. (L. 238)*

Issues Specific to People with Learning Disabilities (Theme 1.2):

Despite these commonalities, most responses emphasised differences. This group presented the therapist with issues unique to, or heightened, by their learning disability. The disability itself was inescapable:

Candace: *Not one client I work with you don't have to, sort of, the issue of disability itself, that's going to come up even if they've been referred for something else (C.519)*

Denny: *I think the work that I've done focuses on the pain of what it means to have a learning disability ... bring the elephant into the room, talk about it, you know. (D.137)*

Clients struggled with their disabled identity, with "otherness". Belinda described one client's fear and James spoke of a woman whose pain was devastating:

Belinda: *His flat mate was calling him Frankenstein [] but I could see for [him] it was more than name calling, it was something he was living. []*

What I felt was coming out of him was strong messages about being something other than "normal everyday", but what this something else was, was extremely frightening erm, and it was like monstrous, Frankenstein. (B. 570)

James: *[I said] "Even though I'm a doctor, I can't fix your disability. [] For the first time ever, she stopped all the screaming and she slumped down until she was on the floor holding onto my legs and sobbing, sobbing and sobbing. (J. 422)*

This grief people had for the loss of their ideal self was a common feature. The spoiled identity led to an awareness of being shamefully different, with the attendant anger:

Denny : When they arrive at my door they are mortified that they have been labelled publicly and shamed publicly [...] the bullying, the name calling, the terror of being "Other", you know, it heightens their awareness of the shame, the guilt that they are not the child their parent wanted, and they can never be the child their parent wanted. The anger that they are not the, [sic] they want, you know, they want to be. (D. 335).

With the negative social implications of learning disabilities, therapists were often faced with their clients' experiences and expectation of rejection. Disrupted attachments and relationships were an expected corollary to having a learning disability. A history of abandonment and abuse was almost universal. There was a recognition that social factors would shape what was brought into therapy:

Graham: The context in which people are living is different you know the social narratives, the cultural narratives [...] that impacts on the individual who is coming into the therapeutic relationship with you. (G. 347)

The Self as Medium (Theme 1.3): The ways in which people communicated their issues were often very different to mainstream clients. Characteristically, clients used the “self”, through their roles, actions or their bodies as the means by which meaning was communicated. Participants gave examples of the different presentations they faced (see Fig. 2). As Kieran explained:

Kieran: You know this is not conventional work, the person lying down talking about their childhood, erm, you know they may be very, very repetitively banging on the side for twenty minutes and how to make sense of that or what to do about that, it's a challenge. (K. 211)

Specific challenges the participants coped with included literal acting out of feelings. Issues identified (theme 1.2) as particularly resonant, such as abandonment, often provoked strong reactions in parallel situations in therapy. Louise described one client tearing up her letter about holiday dates:

Louise: I think it's all concretely re-enacted, erm, rather than saying that, I think, you might be feeling angry with me, so it's tearing things up because they feel so abandoned. (L. 145)

This was an experience shared by most participants:

Alastair: I've been shouted at, spat at, fists waved at me. (A. 232)

Denny: One little kid actually head butted me. (D. 255)

Learning disabled clients went beyond this physical expression, as therapists had to deal with communication being “embodied” by the client.

Belinda: He picks his plaster away and gouging, gouging away at his cut. (B. 743)

James: She would also harm herself, she would scratch herself, cut herself, her arms were full of scratches and sores. (J. 402)

Louise: There have been other therapists where there's been soiling that happened in the session. (L. 184)

Figure 2. The Self as Medium: Client Presentations

PRESENTATION	BEHAVIOURS	EVIDENCE
AGGRESSION: TOWARDS THERAPIST FOR SELF	<ul style="list-style-type: none">• PHYSICAL ASSAULT• VERBAL / EMOTIONAL ABUSE• DESTRUCTION OF PROPERTY• SELF HARM	A,232: L,143: D,255: E,502 A,237: L,138: D,192: D,253: E,244: E,400: J,156: B,741: L,146: C,397: K,213: E,288: J,402: B,749: S,27: B,426: J,305
EMBODIMENT	<ul style="list-style-type: none">• PICKING• SALIVATING	L,160: L,174: L,220: A,270: J,154: G,43: B,743: S,41
BOUNDARY BREAKING	<ul style="list-style-type: none">• SEXUALISED BEHAVIOUR• BREAKING STRUCTURE & CONVENTIONS OF THERAPY	J,406: C,101: C,395: B,220: B,562: S,88 C,475
SUBMISSIVE	<ul style="list-style-type: none">• “HANDICAPPED SMILE”• PASSIVE BEHAVIOUR• CONCEALMENT	C,41: J,292: C,536: B,547: B,796 K,72: D,282: S,214

Need to Adapt Therapeutic Process (Theme 1.4): Due to the identified differences, and an acknowledgement of limitations from the primary learning disability, every participant remarked on the need to adapt the therapeutic process in some way:

Candace: *I think it is hard to get across to someone who's a psychotherapist, erm, and is used to a client coming in for 50 minutes and then going again, just how different it is to have to fit in with a person.*
(C. 537)

The adaptations identified included simplifying language, slowing the pace of sessions, using and attending to non-verbal communication, using alternative mediums and being willing to try approaches beyond those learnt from standard training. James summed up the flavour of the participants' responses when he said it was about:

James: *Always trying to find a way of getting in touch with the real person that's in there and also by whatever means it takes.* (J. 168)

All participants emphasised the increased value of using transference and counter transference in understanding their clients' communications. Most described this as a critical therapeutic tool for this client group.

Kieran: *You can't work without the counter transference and you know you need to be always paying attention to it thinking about it.* (K. 229)

Overall, the participants described a model in which the theory regarding the person in therapy remained constant, but the clients represented an extreme end of the continuum which was greatly impacted upon by organic limitations, life experiences and presentation related to secondary handicaps. To use and extend a formulation of the factors addressed in psychotherapy, such as Malan's (1979) triangle (see Fig. 3), the conceptual relations within therapy remained constant, but the *shape* (or experience) of the therapy was dictated by the planes of the continuum. (See Fig. 4)

Primary, Secondary and Tertiary Handicap (Theme 1.5): The need to adapt therapy segued into a significant theme for almost every participant, regarding the definition of their role. The tension was generated by the difficulties in identifying the “real” in therapy, distinguishing between primary and secondary handicaps:

Candace: She had these pseudo seizures and when I first started working with her it was absolutely terrifying []. I only started to work out that it was a pseudo seizure when she would start to have them 10 minutes before the end of every session. (C. 384)

Not only did participants struggle with clarifying primary and secondary handicaps, they noted the difficulties in distinguishing between these and *tertiary*, or social handicaps imposed (see Fig.4), often due to dependency.

Figure 3. Malan's Triangle of Person

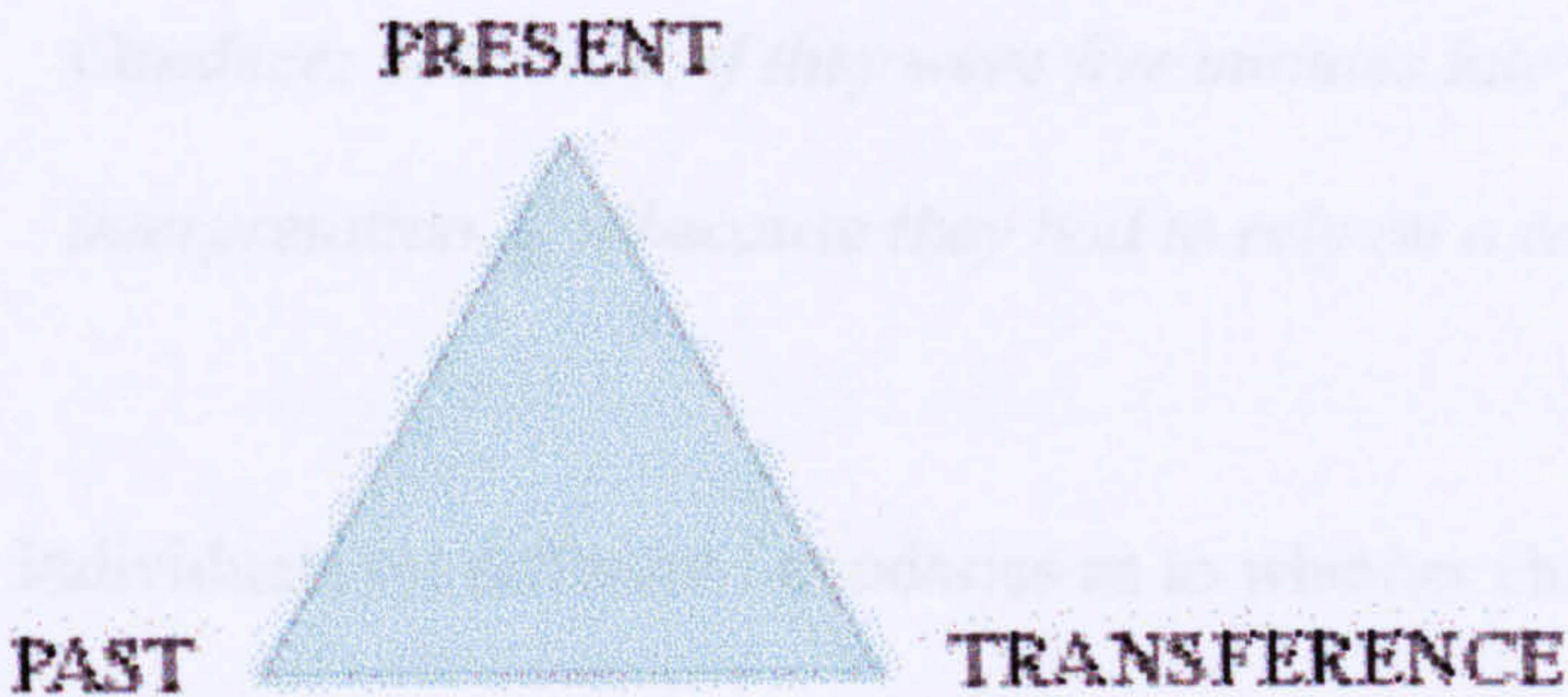
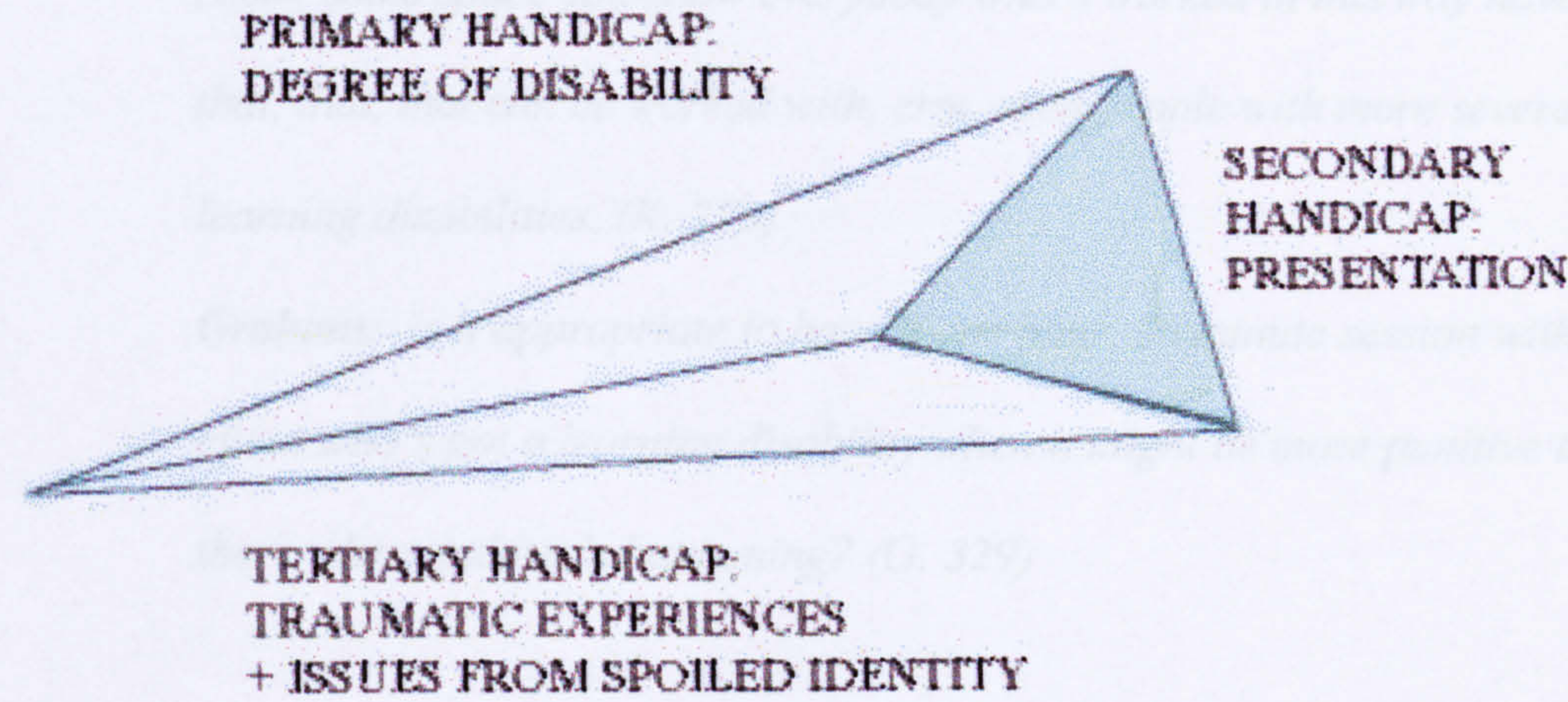


Figure 4. Continuum Model



Belinda: I'm never really sure ... [] sometimes they can have a bit of a moaning session about their workers, and that's an interesting thing, because I, I'm never sure whether it's the clients. (B. 478)

Candace: You know, if they were five minutes late you can't necessarily make an interpretation of it because they had to rely on a carer to get them there. (C. 539)

Individuals set different boundaries as to whether changing the techniques involved in delivering therapy extended to altering the traditional role of the therapist.

Differences were apparent between participants as some issues that were identified as primary handicaps requiring adaptations were also cited as interpersonal processes with intentionality that could be overcome if boundaries were held.

Kieran: Our standard model, therapeutic model, 50 minutes, same, same room, same space you know everybody who's worked in this way have found that, that, that can be worked with, erm, even people with more severe learning disabilities. (K. 275)

Graham: Is it appropriate to have a one hour, 50 minute session with a client who's got a learning disability when it might be more punitive to sit there when nothing's happening? (G. 329)

There was similar confusion at a systemic level. For instance, there was recognition that this client group was at real risk of being damaged by the services on which they were dependent:

Alistair: The therapy ended abruptly because a psychiatrist had decided that he needed to move somewhere else and he would, they had a therapist there so he didn't need to see me any more. (A. 113)

Belinda: [Of a client regularly taken by her carers to watch planes taking off at the airport] They knew she felt abandoned and so why did they take her to a place where she and to watch people going off... there was something I felt quite perverse about the whole thing. (B. 415)

All the participants made either implicit or explicit reference to the social and political system in which people were embedded, recognising a need to work systemically. However, this created a dilemma and most participants were forced to consider whether they had a responsibility to act beyond the confines of the therapeutic session and how this should be done:

Paul: How much , you know, am I willing and able to get embroiled in those kind of messy dynamics for society to work out...the ambivalence and the uncertainty about the role and the responsibilities that go with that sort of broader role, that stays with you if you stay clinically involved in learning disabilities. (P. 239)

A number of practitioners reported working systemically with psychodynamic principles, or working in conjunction with others to control the interface with services, but for some, this broader responsibility necessarily altered the nature of their role.

Denny: There will be so many different agencies involved in their lives and you're part of a cog, you're a cog in a big wheel and sometimes I'm an advocate. (D. 369)

Ela: I care what happens, and I try to put them first. Beyond a kind of, beyond perhaps what I should have. (E. 452)

Graham: I think it works to do that kind of work, slightly more educational. (G. 318)

Overall, the “purity” of participants’ therapeutic roles varied according to the degree to which they felt their psychodynamic model was an overarching concept that could usefully apply to the myriad aspects of their clients’ lives (see Fig. 5) i.e. where the concept of transference could be used to interpret reactions and direct action. Where alternate organic or social theories appeared to be part of the “real”, people struggled to integrate these into their working practice in their clients’ best interests (see Fig. 6). Whilst all participants decided their own boundaries, Belinda reflected the integrative position that providing a service and maintaining the structure of therapy in itself impacted on broader social context:

Belinda: We are actually opposed to erm something that is society's death wish and this idea generally that people that aren't perfect don't have a place in the world and we are working with people showing the world that actually people do have a place in the world. (B. 989)

Super-Ordinate Theme 2: Working With Spoiled Identities

This theme of grappling with the internal and external worlds of people with learning disabilities formed a bridge to the second super ordinate theme, that of working with people with a spoiled identity (see Fig.1).

Evolution as Therapists (Theme 2.1): The participants described very similar experiences which contributed to their working in the field of learning disabilities. With the exception of the two who shared a medical background, all participants had had experience of people with learning disabilities in other roles, prior to marrying this up with psychodynamic psychotherapy. For some, contact was limited, but many reported it as forming part of a narrative in their lives:

Denny: *I suppose my first contacts go back to childhood because my mother was er working as a [professional] in a school [] for young people with all sorts of disabilities. (D. 103)*

Despite this, participants almost universally described their speciality as having been unplanned:

Suzzanne: *I fell into it really. (S. 10)*

Candace: *I kind of ended up in learning disabilities by not really choosing it. (C. 27)*

Figure 5. Dominant Psychodynamic Model

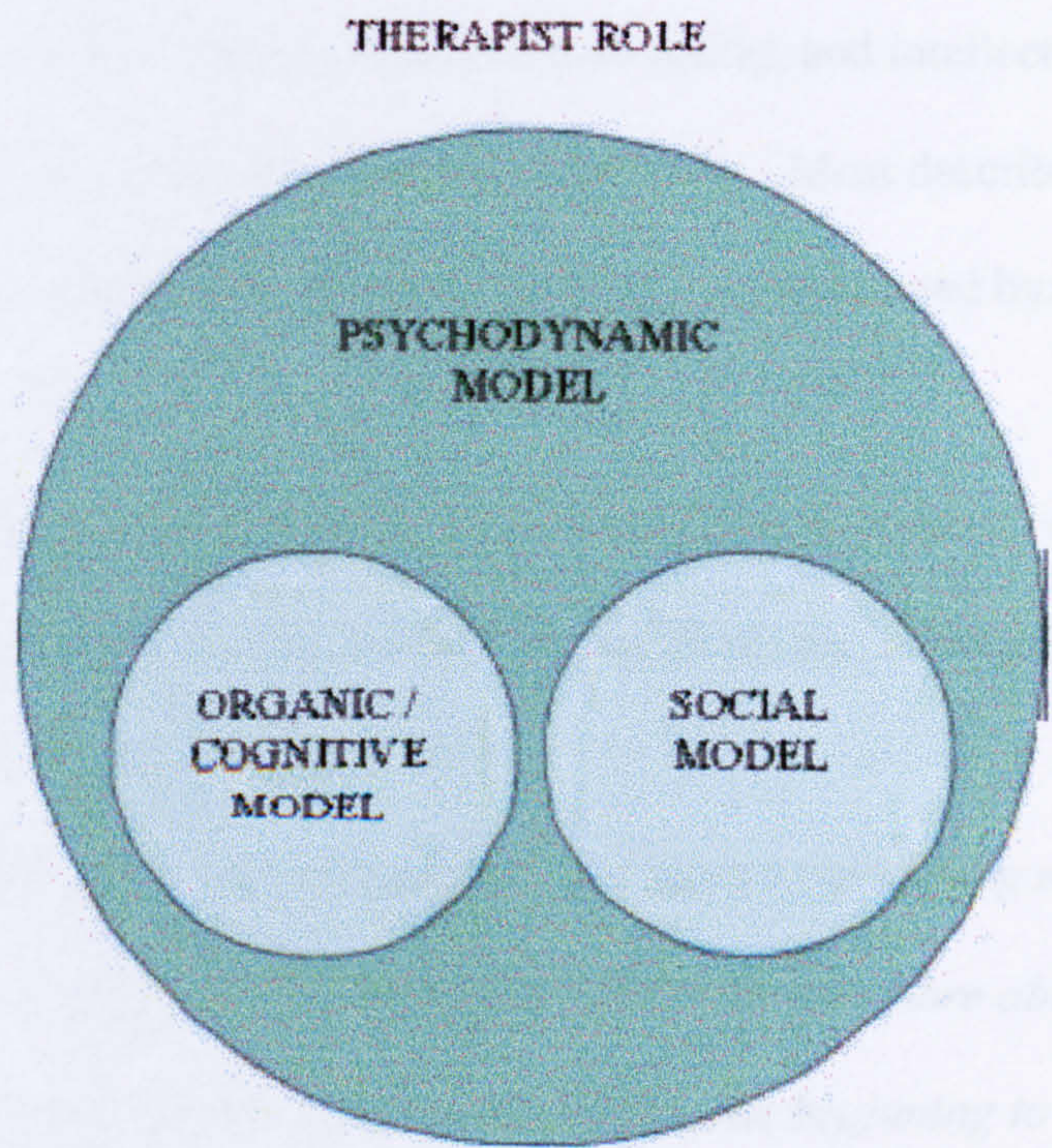
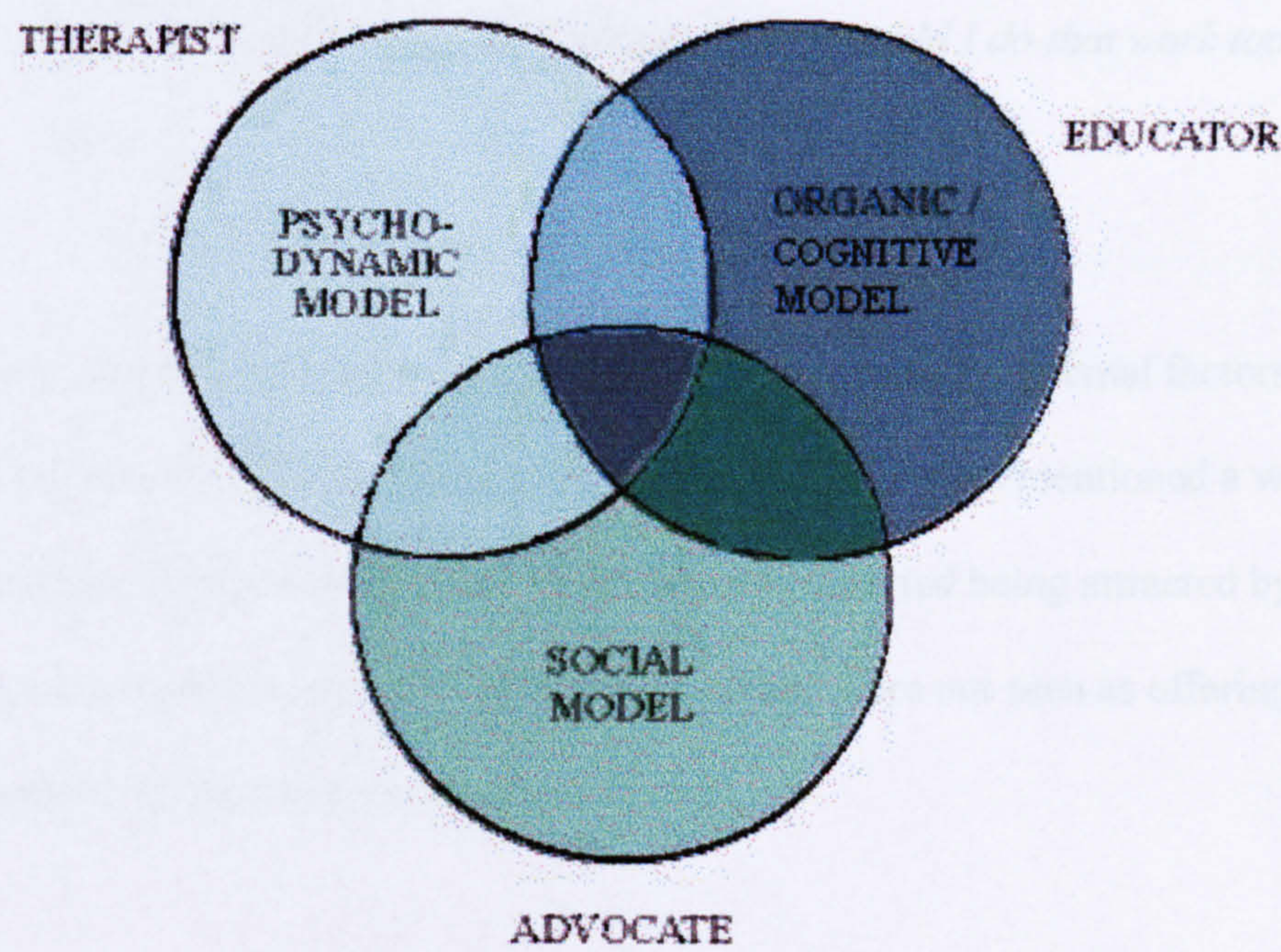


Figure 6. Non-Dominant Psychodynamic Model



The common experience involved an additional two setting conditions; an environment supportive of psychodynamic thinking; and intellectual curiosity about the inner world of people with learning disabilities. Most described a catalyst, in the form of contact with an inspirational “mentor”. As illustrated by:

Louise: I happened to be in a team where, as it turned out, everybody had done this alongside counselling qualifications, so very sort of attuned to the need for counselling. (L. 16)

Graham: I realised that there was more to just doing music than playing the tambourines and playing the piano. It was more about the psychotherapeutic relationship which was beginning to happen between me and some of the clients. (G. 15)

Alistair: I [] got the director of [an organisation offering psychotherapy to people with learning disabilities] to come and do a workshop there, and I sat in on it, it was very interesting, I thought this was a really interesting area. I was interesting in thinking, “Phew, could I do that work too?” (A. 49)

Some participants explicitly acknowledged that there must be internal factors which drew them to work with the client group. A few interviewees mentioned a wish to address social injustice and almost all participants reported being attracted by the challenging nature of the work. Mainstream clients were not seen as offering the same mental exercise and excitement:

Ela: I found our patients completely mind rotting really. (E. 74)

James: With people with learning disability its much more, much more riding a bucking bronco than going for a gentle hack. (J. 185)

Sometimes people reported the challenges of working with learning disabled clients made them question the value of their input:

Candace: [I] can't get any feedback from her about whether what we are doing is helpful to her or not really, that's what the problem is um you know it feels like you're working, working, floundering around a bit in the dark. (C. 416)

Self doubts were a common part of participants' narrative, but despite these, people seemed able to find examples of the value to their work. They explain:

Kieran: I'm a sort of passionate believer in this, as a model, erm, and as a sort of, erm, in, in, in, I wouldn't say curative but [] it helps with life. (K. 153)

James: Explaining learning disability psychotherapy to other people sounds rather gloomy, as if its all about how awful disability is, erm, well there is that but there is, it can be uplifting as well, it can be quite poignant. (J. 440)

Denny: I was never sure what the kids were leaving with, and it's the kids that, who come back to visit to say "Hi", to show me their children, which is ... My God! You know?... say what I mean to them so, and, I do believe that it's been very profoundly moving and worthwhile. (D. 212)

Impact on Therapists (3.2): Despite the enjoyment of the challenge presented by clients with learning disabilities, all of the participants made reference to the wearing nature of the work. Although a few participants made reference to positive counter transferences, it was the negative counter transferences evoked by their clients' issues and presentation which dominated accounts (see Fig. 7). Feelings of sleepiness and anger were strongly represented.

James: I think some of the strongest things are things having difficulty keeping awake. (J. 280)

Ela: I didn't just not like him, I felt like slapping him. (E. 482)

Suzanne: I've never spoken about my murderous feelings towards people [] it would be terribly difficult to talk about my own counter transference. (S. 24)

The self doubts noted in the previous theme were placed in the context of counter transference, as feelings of inadequacy and incompetence were reflected almost universally.

Denny: I just feel devastated at the end of the session I feel absolutely useless, pathetic. (D. 280)

Alistair: I think the work can be affected in a very negative way if you were just trying to keep hold of all these things and thinking you know, "I should be above this", you know, and "This shouldn't flap me" and it does, it does.
(A. 285)

A sense of shame for lack of competence was apparent from a number of accounts.

Where participants identified with their clients, there was guilt for the therapist's non disabled position:

Ela: Every time we have to have a discussion about ending you know I find it terribly traumatic. And I've got somebody at home to talk to you know, I'm not in the position that has no friends and most people dislike. (E. 694)

Graham: That was a real harsh one for me, you know that could have been me. (G. 217)

The otherness, previously recognised by clients, was also uncomfortably present for the participants. This, along with the embodied communication noted earlier, appeared to challenge the therapist in dealing with counter transferences of dislike and disgust.

Alistair: Its like being with the kind of, the, the kind of sex monster kind of fantasy that people might have of, of, of especially with someone with a learning disability. (A. 272)

Figure 7. Participants' Negative Counter Transferences

COUNTER TRANSFERENCE	EVIDENCE
ANXIETY	C,384: C,101: K,84: D,92: D,272: E,306: P,13: B,893
PHYSICAL SYMPTOMOLOGY	J,353: P,366: G,287: L,159: L,76: B,903: D,281: A,282: L,121: D,281: C,365
INADEQUACY	D,51: B,432 : A,285: S,304: D,271: S,187: D,280: C,124: L,142: D,19: D,271: K,100: J,419: C,404: P,285: P,317: S,27: S,187
ANGER	A,240: K,221: E,481: J,156: C,124: C,360: P,90: S,281
DISGUST	E,482: A,277: L,162: L,171: E,565: J,408: C,364: S,52
SLEEPINESS	J,280: S,202: S,141 : D,151: D,272: K,203: C,125: S,144
GLOBAL NEGATIVE COUNTER TRANSFERENCE	L,111: L,151: D,53: D,258: K,225: J,234: J,297: C,99: C,522: P,32: P,192: B,814: B,770: S,232
SHAME AND GUILT	K,204: L,132: G,211: E,626: S,251: E,692: S,232: L,131: D,195: C,405
IMPAIRED ABILITY TO THINK	L,172: K,204: K,227: S,141: S,229

Louise: This person actually launched herself at me in this excited / angry state and sort of actually dug her claws in me. I said claws... (Sounded embarrassed and corrected) fingernails. (L. 81)

Suzanne: I had the sense that he was often testing me as to how much I could, how, how much I could tolerate him, how much he disgusted me. (S. 55)

Participants were placed in the position of able, powerful “other” (most often parents) in the transference. Most frequently, transference involved abusive, critical or abandoning figures.

Candace: It's more common that they make you into an abandoning and inadequate sort of parent. (C. 470)

Kieran: A harsh punishing father. (K. 177)

Whilst all the interviewees used the framework of counter transference to reflect on their experiences in sessions, Louise and Alistair made the point that the impact of these powerful dynamics went beyond the professional role:

Alistair: Its difficult to talk about because it is, it's, you know very personal talking about counter transference, talking about myself. (A. 264)

Louise: I think there's an impact on you as a person, not as a therapist but as a person doing this, it really can't be overestimated. (L. 255)

Just as clients used embodiment to express issues, a similar process appeared to be occurring with the therapists. Physical symptoms were commonly reported:

Paul: We had some very strange biological sensations. (P. 365)

Alistair: He's another example of feeling quite sick sometimes. (A. 287)

Belinda: I did actually leave the sessions with a terrible headache. (B. 904)

Participants wrestled with the interpretation of physical sensations, but the consensus appeared to be that the process of acting as a container for painful emotions could have a physical, as well as emotional impact on the therapist.

James: Sometimes you have to pay attention to whether or not you have simply picked up the latest bug or whether in fact your body and immune system are being assaulted by unconscious things that are being projected onto us. (J. 353)

All participants made reference to the need for good supervision and / or personal therapy to help with the considerable strains of the job.

Kieran: You know you can get more help from colleagues in supervision. (K. 242)

Louise: I think it's really vital to have a good team support and good supervision. (L. 257)

Overall, the participants almost universally described the work as hard, due to the themes identified as differences from mainstream work. The traumatic issues and extremes of presentation, the rethinking of role and process, and the powerful, unsettling transferences affected relationships significantly.

Louise: I think what the impact it has on the therapist is [] sort of hard... hard and constant there isn't the light relief of being able to, erm, sort of, you know, the therapeutic alliance where the therapists and patients play or think together so those spaces are so much harder to find, (L. 151)

Candace: It was so difficult to spend a couple of minutes with someone who comes in in a wheelchair, who doesn't talk to you for the whole time. They might have some scary looking thing that looks like a seizure or might go to sleep or, you know, give you very little response at all. (C. 99)

Candace notes the strains of addressing secondary handicap, whilst Louise's quote accorded with Symington's (1981) description of despair when faced with the apparent organic damage of primary handicap. Paul made reference to this and extended the concept to encompass social networks, suggesting that the tertiary handicap also impact on therapists:

Paul: Its very emotionally draining work to do over long periods of time, changing resources, changing climates, changing policies, the whole lot, so systemic despair is probably the malady of this century. (P. 194)

Courtesy Stigma (Theme 3.3): The social context described above was a constant backdrop in people's narratives. The participants were very aware of the social stigma attached to learning disabilities and were aware that their clients had previously been denied opportunities, Alistair illustrated the unoffered chair:

Alistair: I don't think he had ever had this kind of dialogue with anybody, no one had really sat down with him in a way, that would have allowed him to explore, you know, some of these complex thoughts and fantasies that he had had. (A. 129)

The therapeutic marginalisation process was identified not simply in clinical settings, but permeated the structure of training provided to fledgling therapists:

Alistair: Certainly during my training it had never come up, never. You know, not even mentioned. (A. 63)

Kieran: I just remember [] having a sense that I don't have any training to do this, my training hasn't equipped me for dealing with this. (K. 100)

Candace: Every time I brought a case they turned it down, bring another one turn it down, bring another one turn it down, really they didn't want to supervise a learning disability case. (C. 206)

Closer inspection showed that for most, the therapeutic disdain identified for clients extended to those working with them. There was an awareness that working in this manner with this client group could leave one open to being undermined or even attacked by others:

Ela: People were very hostile to you, and if you tried to make anything different people were incredibly, incredibly unpleasant just to the extent of not even being civil, because you know their conviction that people with learning disabilities was hopeless was so strong. (E. 353)

Louise described an experience of attending a professional conference where a paper on work with people with learning disabilities was presented. She recounted:

Louise: People did find it very hard, they were terribly moved by it but some people were angry and said, "How could you call this psychotherapy?" (L. 228)

The reality that clients were inextricably embedded in a network of colleagues and carers meant that people felt vulnerable to the negative judgments of others in a position to view their work. Interestingly, the attacks on competency which were felt by many therapists as part of the counter transference were experienced again at a systemic level:

Kieran: She wanted to go out into the corridor and I was trying to get her back into the room [], in fact my manager getting very concerned about me coming out, "Are you OK, is everything all right?" (K. 95)

Denny: [when talking about a colleague's disdain] I don't know whether if that's about me or about the client group we're working with and [] the defence mechanisms that come into play and the feelings of inadequacy and stupidity that get projected. (D. 61)

Candace: I found myself being sort of behind everyone else because I started late and then you know, [named learning disability colleagues] were saying to me, "Oh, you're the person with the learning disability." (C. 227)

Candace and Denny's comments indicated an explicit awareness of being identified with their clients, and having characteristics projected into them by others and being subjected to the courtesy stigma described by Goffman (1963). Some comments imply that this identification could not fail to influence work practices:

Graham: What I've always tried to is to balance the learning disability work that I do [] and also my non learning disability work because I think that, think that you need that balance to have that kind of credibility. (G. 90)

James: Fortunately there was nobody else around so I felt brave enough to try something different. (J. 417)

Discussion

Relating Results to Previous Research

Despite the similarities with non-learning disabled clients, it was the differences in presentation and issues which predominated in accounts, echoing Mannoni's (1973) stance that work with this group was uniquely challenging. There was overlap with theoretical models, although participants placed differing emphasis on the elements described. For example, Hollins and Grimer's (1988) three secrets of disability, sex and death were represented amongst the issues which emerged. However, the two latter issues were not as well represented in participants' reports as might have been expected. The theme of abandonment was more strongly represented than death *per se*.

The theme of disability itself was universally raised and identified as central to work with the client group. Participants' reports that clients recognised the limitations imposed upon them by the condition, and showed an often acute awareness as to how they were perceived by others accorded with findings of other researchers (Jahoda *et al*, 1988; Szivos-Bach, 1993).

Secondary handicaps (Sinason, 1986) were identified by participants and often underpinned presentations that were quite distinct from other client groups. Examples of identification with Wolfensberger's (1972) stereotypes, for instance, as "menace", "object of unspeakable dread" and "diseased organism"(p.20-22) were given and recognised both by the participants and the individuals themselves.

These roles made up part of the social context in which the therapist was inextricably embedded. This accords with the “ideological counter transference” described by Retzinger (1998) in which the therapist is faced with the task of separating out belief systems before being able to connect with a client as an individual.

Participants agreed that counter transference was a key therapeutic tool in finding meaning in these presentations and gave it greater importance than was afforded in previous descriptions of therapy. In Jackson’s (2004) review of fourteen descriptions of therapy, counter transference was highlighted as a therapeutic tool in only five cases.

The manner in which clients communicated feeling resonated with Perry’s (1990) definition of acting out. Specific behaviours such as submissiveness, aggression and boundary breaking, matched those of previous case descriptions (Ruth, 1999; Symington, 1981; Korfe-Sausse, 2004)

The embodiment of communication was widely described and echoed case material by several clinicians who noted the use of faeces, mucus and saliva in a way that communicated feeling (Sinason, 1992). The findings resonate with Bick’s (1968) concept of “psychic skin”, with clients literally using skin to communicate discomfort and distress. The transferences described also reflected those described in previous cases, although maternal transference was less prominent than might have been supposed (Jones and Bonnar, 1996; Mannoni, 1972)

The technical adaptations reported involved a more flexible approach to medium, language and the use of non-verbal channels. These adaptations matched those in other published case descriptions (Bungener and Mc Cormack, 1994; Hodges, 2003)

Whilst adaptations of method were commonly agreed, the findings highlighted a schism amongst practitioners' roles which has not received much attention in the literature. The degree to which practitioners acknowledged the need to work with systems appears to mark a shift in practice. Freud (1917) considered the intrusion of carers to be dangerous, whilst Mannoni (1972) noted the importance of information gathering from parents. Jackson's (2004) review showed that a third of clinicians reviewed appeared to incorporate third parties, whilst almost all of the participants in this study reported this to be an accepted part of their work.

However, the way in which therapists interfaced with systems reflected a divide. Stokes' (1987) had observed the inherent difficulty in distinguishing between primary and secondary handicaps, but participants were indicating that it may be equally difficult to distinguish these from tertiary or societal handicaps.

The introduction of the idea of a tertiary handicap reflects the societal stigma models, based on Goffman's (1963) work. Social factors had previously been seen as influences on the psyche but outside the range of the therapeutic sessions. Here, the participants varied as to whether they exclusively espoused a psychodynamic model or whether they took on roles not previously encompassed by this model.

Another corollary of the stigma model which could be applied to the data was the area of social comparison (Gilbert *et al*, 1995). Some participants had been explicit in recognising the dynamic of comparison within the therapeutic relationship.

Although largely neglected in the literature, this counter transference had been noted by Sinason (1995) and Reyes-Simpson (2004) who identified feelings of envy in the client and complimentary guilt from the therapist.

This dynamic of the “dis-abled” client and the able therapist appeared to reflect shame and guilt states. Gilbert et al (1994) note that in guilt states, the self feels intact and capable, yet is the source of hurt to others. Shame states are characterised by the self as un-able; afraid, helpless or passive, inferior, the object of scorn disgust or ridicule, with poor functioning, for instance one’s mind going blank. Also characteristic of the phenomenology of shame, was anger towards the self and anger towards more able others.

When client presentations are viewed collectively, there appears to be a strong similarity, with aggression towards the self and therapist and submissiveness featuring strongly in accounts. The less observable features of shame are represented in the participants’ descriptions of their transference experiences. Explicit references to shame, anxiety, inadequacy and impaired ability to think were recurring themes. The findings that internalised shame correlates both with abandonment experiences (Claesson & Sohlberg, 2002) and stigma (Lewis, 1999) would seem to fit with the specific issues identified for this client group.

This combination of observable presentation and counter transference experiences suggests that the individual features of psychotherapy with this client group may be reformulated as indicative of shame proneness or shame states. Thus shame may represent a more detailed component of the cluster of issues subsumed under Hollins' (1989) concept of the disability itself.

The professional context in which participants worked showed signs that courtesy stigma (Lewis, 1999, Mitchell, 2000) was being applied, particularly from psychotherapy colleagues. There is little evidence that the profession was recognised this or was using psychodynamic models to consider their exclusory practices.

All the participants described the work as arduous, and suggested that "spoiled identities" were intrinsically traumatic, to both client and therapist. This resonated with Hollins and Sinason's (2000) attempt to equate learning disability to the diagnostic definition of trauma (American Psychiatric Association, 1994)

Despite difficulties in reconciling the element of "suddenness" associated with the definition, some data fitted with literature on vicarious trauma. Pearlman and Saakvitne (1995) described this as the impact on an individual's inner world through empathic engagement with others' traumatic material. This was illustrated by the comments on how the counter transference went beyond the professional to the personal; the therapist role did not always protect the individual from the material.

Methodological Limitations

The study has a number of methodological limitations. One concern arose over the cultural homogeneity of the sample and researcher. Accounts by therapists from ethnic minorities were not available, and results might therefore be expected to reflect a cultural bias and limit transferability of findings. However, this may genuinely reflect the nature of the profession at present.

Another significant issue related to the sample was that almost every participant reported contact with the ideas of a small number of key theorists. There would therefore seem to be a risk that the data reflects a common learnt model rather than unprocessed experiences. However, just as Smith and Osborn (2003) recognised the impossibility of being a truly naïve investigator, the naïve participant is neither possible nor useful in terms of transferability of data.

This may beg the question of whether the data from the study would have been on safer ground if interpreted using the principles of grounded theory.

However, the aim of the study was to investigate the experience of the therapist, despite the “triple hermeneutic” implied by their roles.

As in any qualitative research, the issue of subjectivity needs to be addressed. The author’s prior interest in shame phenomenology needs to be acknowledged. Whilst observations were supported by textual evidence, other interpretations may have been overshadowed by the researcher’s area of interest.

Clinical Implications

Findings suggest that clinicians in this field may be at risk of compassion fatigue or vicarious trauma, so support networks such as supervision need to be viewed as essential in the work. In particular, tools for managing negative transference need to be explored or there is a risk that the experience of therapy will be unhelpful to both parties (Storr, 1979). Ideological transference may need to be addressed both by individuals and by the systems and professions in which they operate.

Significant thought needs to be given to the resolution of the role dilemma, by determining the nature of the implicit schemas upon which decisions are based. Tertiary handicaps appear to have a significant impact on both client and therapist, regardless of which model predominates.

The implications of not explicitly recognising the shame dynamic are potentially far reaching. Shame proneness has been linked to both inhibition and generation of expressed anger, enhanced denial defences and reduced disclosure (Lewis, 1971; MacDonald, 1999; Retzinger, 1999), and if left unrecognised, can lead to failures in therapy (Frey *et al*, 1989).

Future Research

Research on how psychodynamic principles can be applied within networks for dependent adults appears to be a crucial area to explore to help clinicians determine their responsibilities in the face of the added complexities of this client group. The role of shame appears to be a significant avenue which has been alluded to, but not sufficiently explored with learning disabled clients and their relationships. Further

investigation is needed around the attitudes held by clinicians around offering psychotherapy to this client group with a particular focus on the phenomena of ideological counter transference and stigma. Detailed analysis of the evolution of therapists in this field might be of interest with regard to recruitment.

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Part Three: Critical Appraisal

Introduction

In her comprehensive review of 2005, Morrow proposes four standards which indicate the “goodness” of a piece of research. These are subjectivity and reflexivity, adequacy of data, adequacy of interpretation and social validity. In this section I shall consider the methodological limitations of the study with reference to these standards. The clinical implications of the findings and their impact on future investigations will also be examined. The section concludes with a personal narrative of the research process.

Methodological Limitations

Adequacy of data: Perhaps the first question to be asked is that of whether the study includes sufficient quality of data to ensure transferability. Transferability is the criteria which parallels the notion of generalisability in quantitative research, and relates to the extent to which the findings may be considered applicable to other settings.

A number of factors may contribute to transferability in the present study, including participants. Whilst clearly lacking power in quantitative terms, eleven participants appear to be sufficient for an ideographic as opposed to nomothetic methodology. Guest *et al* (2006) report saturation occurs within twelve interviews, with the basic super-ordinate themes present after six accounts. IPA does not, in fact, require saturation, studies being published with as little as one participant (Smith & Osborn, 2003), so the current sample would seem able to generate necessary and sufficient data.

IPA requires the sample to be purposive, and membership criteria of the IDP would seem to clearly relate to the qualities and experiences that would be relevant to the research

question. However, the very specificity of the sample may raise concerns over what might be described as “tautological sampling”. Due to the stringent membership requirements, the IDP represents a very homogenous group. Almost every participant mentioned exposure to the ideas and publications of Valerie Sinason and studied at one of the few institutions offering training in psychodynamic approaches for this client group.

The question needs to be asked as to whether the homogeneity of the sample means that the findings do not reflect peoples’ actual experiences but their predisposition to interpret events via a common learnt model. The high degree of agreement with participants accounts and the descriptions from the literature might be interpreted in this light. As a methodology, IPA can be criticised for its underlying belief in language as being representationally valid. This sample highlights the problem inherent in the constitutive role in participants’ language.

This would seem to be a risk particular to this professional group as psychodynamic therapists are expected to use personal experience to interpret that of their clients in the form of transference. Whilst IPA is often described as a “double hermeneutic” process, the current study could be characterised a “triple hermeneutic” with the participants interpreting their own experience in order to understand that of their clients and in turn, being interpreted by the researcher. With such sophisticated accounts there is a concern that what is described is not genuinely phenomenological. Participants’ accounts are already imbued with explanation rather than description.

This may beg the question of whether the data from the study would have a better fit with the principles of a different qualitative methodology. However, developing a model of

interaction from the principles of grounded theory would ignore the fact that the basic experiential building blocks had not yet been explored. Similarly, the use of a discursive model would have explored the social role and readjusted the focus to the language rather than the individual. Whilst this might be a fruitful means by which to explore concepts such as courtesy stigma, it perpetuates the focus on roles, when what has been unexplored in the literature is the relationship between individuals.

Epistemological complexities are raised by the nature of the participant group but these can be acknowledged rather than resolved, as to use other methodology would lose the essence of the enquiry. To use the argument of *reductio ad absurdum*, therapists would be disbarred from any enquiry as to their inner world because of the risk of tapping into the very constructions they need to fulfil their role.

The quality of data is also measured by the quality and depth of the interviews. The interviews were framed within the IPA model, where brief neutral questions were used to minimise leading. There was a tension here between the need to manage subjectivity, and using techniques to verify, clarify and interpret participants' responses in situ.

As a researcher new to the qualitative approach, I had undertaken a practise interview to learn the technique, and in this it was apparent that my unstructured questions were often subtly leading. In this study, I was anxious not to contaminate the data with leading questions, and therefore made a conscious decision to limit unscripted input during data collection. Whilst this minimised this risk, it also meant that rich data or clarification may have been lost by the limited use of funnelling techniques. However, it was apparent that

prompt questions were not universally applicable to the interview situations, whilst the adaptations were open to question with regard to neutrality.

Using multiple data sources is recommended for qualitative research. Additional means of collecting information in this study might have included participant journals, focus groups and multiple interviews. These were discounted due to the time available, and the financial constraints of travelling to participants, all of whom were based over 100 miles from the researcher. The multiple data sources used were therefore confined to field notes, interviews, participant checks and interviewer observations.

Morrow (2005) cites the need to pursue adequate disconfirming evidence. Whilst there were contradictions between accounts, which might have been pursued further in an extended report, these did appear to be minor and few. More attention could have been given to Ela's account, as this differed from the others with a sociological rather than psychodynamic perspective. However, whilst her account may have had different emphasis, e.g. on pragmatics and systemic issues, there was still a high degree of agreement with identified themes. Where significant disconfirming evidence was apparent, across accounts, this was highlighted as a theme in its own right (e.g. Primary, Secondary and Tertiary Handicap).

The participant checks were another instance of inviting disconfirming evidence. However, there was a risk of tokenism as the two participants approached did not disconfirm any of the analysis shared with them. Their preferred method of using email communication may have inhibited a more engaged discussion about the data.

Managing Subjectivity and Reflexivity

As in any qualitative research, the issue of subjectivity needs to be addressed. Firstly, most standards advise making one's implicit assumptions and biases clear at the outset of the project. To this end, a profile of the researcher, providing a context for involvement in the study and personal biases, has been included in the thesis to promote transparency of process.

Following the guidelines of Glaser and Strauss, (1967), the literature review was not undertaken until the semi structured interview had been constructed and protocol decided. However, I had a broad awareness of the findings in the field due to my general reading and specific interest in psychodynamic psychotherapy.

As researcher, I tried to adopt a reflexive position by keeping a field diary to record experiences and thoughts which were used during the writing process to check for assumptions. Further safeguards were included by checking the initial transcript with an independent reviewer, and comparing findings (see Appendix F.iii)

However, one dilemma which arose as part of this process of managing subjectivity was the tension between managing bias, and two of the identified quality standards, those of reflexivity and ontological authenticity. Ontological authenticity relates to the need to expand and elaborate on the participants' constructions, it might be seen as the process which looks in depth at the participants' experience, and goes beyond the descriptive to the interpretative.

The specific tension between these concepts for this study lay in my awareness that I had a pre-existing assumption that shame experiences would be represented in participants' accounts of working with this client group. Initially my approach to managing this was one of "bracketing" (Morrow, 2005) in which I set aside my assumptions to avoid influence on the research. However, I was increasingly aware that all participants had either directly referred to shame or described its phenomenology without labelling it as such. Whilst usually minimising use of the funnelling technique, on one occasion this was used to clarify a passing reference to shame and guilt. The respondent, Denny, replied emphatically that shame was without doubt present in every one of the clients she had seen.

The pervasiveness of the phenomenon in other accounts and Denny's emphatic answer seemed to illustrate confirmability, so this was included in the report as a significant and valid theme. However, it may not have been given such prominence had I not been predisposed to notice its presence or phenomenology. Glasson (2004, p. 93) was clear for the need to exclude "the beliefs, pet theories, or biases of the researcher". Yet without an awareness of the shame literature it is unlikely that I would have noticed and grouped the descriptions into the one concept, and probed further. Whilst this did produce what appears to be an ontologically authentic conclusion, my sensitivity to shame phenomenology may have overshadowed other interpretations of the data. Ultimately, however, my position was one of recognising my explicit bias, cross referencing it with the data and agreeing with Morrow's (2005) position as she states:

“I would argue that the investigator always believes something about the phenomenon in question and that a greater grounding in the literature militates against bias by expanding the researcher’s understanding of multiple ways of viewing the phenomenon.” (p. 254).

Adequacy of Interpretation

Adequate interpretation of data requires sufficient immersion in the data. It is hard to quantify what “sufficient immersion” entails, but for the current study, this was addressed by listening to each tape in conjunction with the transcript at least once. The transcripts were then read and re –read.

One difficulty with the immersion process was that the sheer amount of data was overwhelming. With over four thousand lines of data being generated by participants, the risk of overlooking subtle themes, because they could not be retained easily, was significant. The difficulty of creating a coherent structure was addressed by using visual display techniques to help with conceptualisation. Where themes were identified using the IPA analysis techniques, the relevant text was physically cut and pasted to form a wall to ceiling display of related concepts. The relevant text could be viewed as a group, to further identify commonalities and differences, helping the refinement process. In this way, the risk of disregarding or overestimating a theme was reduced, and interpretation was grounded in examples.

Clearly, the process of writing the report is part of the iterative process, and this was recognised in the ongoing changes made to the drafts. One difficulty emerged due to the condensed form of the report. The report was written to match the criteria of the Journal of Applied Research in Intellectual Disabilities. This meant that information needed to be

highly condensed, which may have been at the cost of rich detail and more comprehensive presentation of the material.

Social Validity

Social validity may incorporate reflection on the appropriateness of the aims of the study, its process and its ultimate contribution. Key to the process is the ethical obligation of researcher to participants. The risks in qualitative research are often seen as the impact of the questions upon participants. It was assumed that the experiences discussed in this study might remind participants of uncomfortable feelings but the nature of the sample was such that the process of acknowledging such feelings for a therapist was expected to be a familiar and even welcome process.

In the event, no-one showed indications of distress. In the literature, where distress had been noted for participants, researchers have found little evidence of long term effects (Turnbull *et al*, 1988, Corbin & Morse, 2003).

Benefits to participants have been hypothesised to include the opportunity for cathartic experience, self-acknowledgement and validation, the contribution to a sense of purpose and increased self awareness (Corbin & Morse, 2003).

Whilst none of these were directly described by the participants, several people commented on their belief that it was important to further the knowledge in the field, and that they were pleased to be able to contribute.

Oliver (1992) reflected on the social, political and ethical implications of exploration in this field. As he says:

“Research on disability has had little influence on policy and made no contribution to improving the lives of disabled people... the process of research production has been alienating for both disabled people and for researchers themselves.” (p. 101)

There is a risk that interviewing therapists may perpetuate the disempowerment and alienation of clients described by Oliver. The service user representative questioned why the research was being conducted with therapists rather than the people with learning disabilities.

One of the initial drivers for the research was the recognition of the “unoffered chair” (Bender, 1993). Since access to services appears determined by individual clinicians this shows therapists to be of supreme importance when determining whether services are developed. Therefore, there appeared to be a *prima facie* reason to explore individual therapists’ experiences.

However, one of the authenticity criteria named by Guba and Lincoln (1989) is that of *catalytic* authenticity. This refers to the extent to which research can be justified in that it prompts action. Patton (2002) speaks of the similar concept of *consequential validity* in achieving social and political change. The degree to which the findings of this study may prompt action are still speculative.

Clinical Implications

So the question remains as to what specific findings may be relevant in promoting action? Firstly, whilst people’s narratives as to their evolution as therapists’ were ideographic, one common element was the contact with theories of psychodynamic work with people with

learning disabilities. This is necessarily dependent upon the extent to which information and experience of this manner of working is accessible. Thus, wide dissemination of information would appear to be recommended to catalyse predisposed staff. The findings highlight the need for peoples' work and experiences to be made accessible. Highlighting the positive challenge of the work may be particularly effective in inspiring prospective practitioners.

For the purpose of social validity, dissemination has been included in the process for the current study, involving both client groups and colleagues.

From the available literature, the emphasis and content of the dissemination process thus far has been *client based*, justifying the inclusion of clients with learning disabilities on the grounds of emotional intelligence and the demonstrable effectiveness of the interventions. The study suggests that this has been effective in piquing the interest of therapists with certain setting conditions.

However, the wider implications of the findings as to what may be valuable at this stage may indicate taking a *therapist based* approach. This could involve using psychodynamic and shame models to explore exclusion. There may be a huge legacy of stigma which determines the ideological counter transference we may have with people with learning disabilities, unrecognised even by those specialising in identifying unconscious processes. There is need to recognise the contribution this client group can make, rather than perpetuating a societal projection of worthlessness.

Using the psychodynamic and shame models to discuss the meta – dynamic within the therapeutic community may clarify the role courtesy shame plays in limiting the development of services and training opportunities.

At an individual level, the implications for the aims and the role of the therapist for this client group are less easy to identify. Rather than indicating a clear direction, the findings suggest that there needs to be an ongoing exploration of the tension between psychotherapy in its purest application, and the need to engage with the implications of the “tertiary handicap”. Participants are clear about the ways in which they have adapted intra-session techniques to keep the principles of psychotherapy whilst adapting to the individual’s limitations. Perhaps the focus now needs to be on how similar adaptations can be made to allow applications at a systemic level, without losing the therapeutic stance.

Whilst the findings have emerged from the experiences of psychotherapists, they may have implications for the relationships others have with this client group. Whilst generalisability cannot be guaranteed, due to the issues discussed previously, it is not unreasonable to postulate that similar responses may be evoked in carers and staff. Thus, using a psychotherapeutic model to understand the relationships around individuals and groups with learning disabilities would seem valid.

Further Research

The clinical implications above naturally suggest fruitful areas for further research.

This study was unable to pursue a detailed exploration of the early stages of therapists’ evolution in this field. The data suggested that there may be a mine of rich data to be found from qualitative studies focussing on the contemplative stage of pursuing an interest in therapy with this client group.

The area of shame research would appear to be hugely significant in terms of its potential relevance to clients and workers in this field, for instance determining the degree to which clients experience state shame, and shame proneness, and how this impacts on relationships with others. Andrews (1998) notes the myriad difficulties in operationalising shame. The most common form of measurement, that of questionnaires, is problematic for those with learning disabilities and may be both insensitive to the different nuances of shame experiences or unable to distinguish between general negative affects. Direct questioning may be one way to explore this area, particularly given that it is an emotion of concealment. Gilbert has had success in addressing the issue using a focus group format (Gilbert, 2004). This may be a particularly valuable methodology for clients, whom participants reported freely discussed the common shaming experiences of being bullying and teased.

Eliciting the experiences of clients with learning disabilities brings with it difficulties in terms of ethics of consent and practicalities of data gathering. However, this does seem a vital avenue to struggle with, both in terms of knowledge and in recognition of the potential alienation of clients from the research process.

Exploring the way in which therapists manage the interface with networks could be investigated to clarify how clinicians set their boundaries and the consequences of these decisions. A range of methodologies including questionnaires, semi structured interviews and focus groups might be appropriate here.

Finally, the epistemological problems identified for this particular purposive sample may be clarified by designing complimentary studies to this, for participants with different roles with regard to people with learning disabilities, who have not received training in psychotherapy. This would be valuable in clarifying whether the current findings are indeed generalisable, and inform the debate regarding how best to manage carers and systems around clients.

Personal Account

In this section, I aim to write a commentary on the process of carrying out this piece of research. This will include the origins, implementation, and difficulties encountered from the researcher's point of view. The section concludes with a summary of the learning outcomes from the work with regard to future practise.

Origins of the Project

“Do you know what it’s like to have a learning disability? It’s like a dog on bonfire night when boys tie fireworks to its tail and stand around laughing.” (J. B., 1992)

The description above was given by a client who was trying to make me understand what it felt like to have a spoiled identity. The power of her words has stayed with me over many years and left me with a profound need to know more which translated into themes of interest for future research.

I initially entered the Sheffield Doctoral course with a proposal for research relating to the issue of identity in people with Down’s syndrome. This was to have been a quantitative

and qualitative study with participants with learning disabilities. However, recruiting the eighty participants identified as providing sufficient power was impracticable. This was a point of profound frustration, and highlighted the tensions between the pragmatism instilled in me by my role as a clinician, and the need to avoid risk taking to ensure that I met the academic standards required.

This resulted in the uncommitted pursuit of two other research proposals, before the current study was adopted. I retained my interest in wanting to examine the impact of a learning disabled identity but the time constraints led me to examine the issue of therapy from the clinician's perspective rather than the clients'. This was due to the historical difficulties of obtaining ethics approval for projects involving direct contact with people with learning disabilities.

Implementation

The first draft of the research protocol was ready for submission in November 2004. However, shortly after this, my mother, for whom I am the main carer, became critically ill and as a result my registration was suspended. The project was restarted in the autumn of 2005. The proposal was submitted to the Research Panel in December of that year, and final approval was given in March 2006.

A consultation meeting with the service user representative was held the following month. This proved interesting in that it highlighted an important but difficult dilemma. The representative particularly raised the issue of the need for me and participants to use respectful language when speaking or writing about clients. Whilst I had confidence that respect would be shown, I was also aware that the issues raised could and indeed should

address some painful and sometimes unflattering issues about disability. Honest but painful language was likely to ensue.

The difficulty raised here was that to adhere strictly to the service user's request would undermine the purpose of the study in taking a detailed look at the real relationships people with and without learning disabilities had with each other. Sinason (1992) had written about the way in which terminology was changed to avoid the pain inherent in the topic and there seemed to be a risk of something similar happening in the research process.

I was initially anxious about how this might be resolved. I was concerned that the subtle differences between using respectful language, and the respect shown in honest descriptions may not be apparent to the representative, who by the nature of his position had some cognitive limitations and an understandable emotional investment in how he and those he represented were portrayed.

The issue was resolved by explaining this to the representative in letter form, and then discussion of examples from the completed study (see Appendix G.). In the event, the distinction was understood and agreed upon.

Submission to the University Ethics Sub Committee followed, and approval was given (see Appendix B.). Although further ethical clearance was considered unnecessary, I retained some concerns regarding the recruitment of NHS staff as participants and arranged to discuss these with key members of my employing NHS Trust in April 2006.

Following informal discussion around the principles laid out in the Governance Arrangements for the NHS Research Ethics Committees, it was agreed that recruitment was on the basis of IDP membership and personal experience and confirmed that further ethical permissions need not be sought. The way was then clear for the recruitment and data collection stages of the project to be implemented.

The Institute of Psychotherapy and Disability was successfully approached for permission to contact its members in May and responses from potential participants were received from then until September 2006 (see Appendix D.). Seven interviews took place in June, with a further four between July and October.

Data analysis took place concurrently and an initial draft of the thesis was provided to my academic supervisor in October. Amendments were made prior to submission in November 2006. Dates were set to disseminate the information to colleagues, the Advocacy and Self Advocacy groups in November and December 2006.

Supervision

Supervision had been somewhat problematical, in that my initial supervisor had unfortunately experienced difficulties with his health resulting in a significant period of time whereby no supervision was available. Peer support and supervision, which had originally been set up with my cohort and the previous year's intake, was unavailable due to most of the group having either abandoned or suspended their studies.

The provision of a new supervisor had been helpful. However, access was difficult both due to geographical separation and the supervisor's high level of other commitments. As a

result, other than three meetings in 2006, contact largely took the form of email communication. One significant drawback was that both the medium, and awareness of other heavy demands on the supervisor's time, meant that it was difficult to ask detailed questions, or have creative discussions around the process.

Motivation

Motivation proved to be the greatest barrier to the work. My initial enthusiasm had been diminished by the false starts to the project. The loss of a supervisor and support group had left me feeling very isolated with few external prompts to maintain momentum.

My confidence had also been eroded by the previous coursework assignments. I was unpractised at academic writing, having been working in a field where the emphasis was upon making material accessible to people with learning disabilities. Despite successfully completing all the other assignments, I found it hard to gauge the required standards and I began to doubt whether I was capable of completing the degree.

At the point at which my registration was reactivated, from having had complete confidence in my academic abilities, I was now seriously considering abandoning a course for the first time in my academic career. Supervision proved invaluable at this point, giving reassurance and direction. In fact the finite time available, whilst a drawback in that even slight delays in the implementation process raised considerable anxieties, was actually helpful in focussing my efforts. However, the anxiety that course might be critical rather than educational or facilitative meant that the process was unremittingly stressful.

The process itself posed a challenge in learning about the approach, which I had not be familiar with previously. The interviews proceeded quite smoothly although in retrospect I would have wished to felt freer to pursue points of interest.

The process did however, make me give more thought to the ethical processes. The hesitancy of one participant to talk about his counter transference experiences made me realise that, whilst having been clear that the aims of the study were to elicit personal experiences, I had actually been assuming that peoples' responses would not be of concern because of their professional status. As I wrote in the field diary after the interview:

“Realised that it was a brave admission for the participant. I wonder if I have been a little blasé about the impact of the interviews?” (Field diary, Tuesday, 8.8.6)

I had not been aware of the contradictory position I had been holding until that point. Following this interview, I took greater care to gauge the emotional responses of the participants, to check wellbeing.

Future work practise

In terms of future practise, the project provided me with a valuable overview of the logistical aspects of research process, which had changed considerably in the years since my last study. In particular, the experience highlighted the need for comprehensive ethical consideration and the importance of incorporating user views, whether direct or indirect involvement. The potential dilemmas in this field are not resolved, but I have a heightened awareness of the philosophical positions involved which should inform my attempts to find working resolutions to such dilemmas.

The project introduced me to the field of qualitative research, which expands the repertoire of methodology upon which I am now able to draw, and honed the skills necessary in writing to publication standards. I also have a greater awareness of the ethical obligations upon the researcher.

Finally, one lesson was drawn from the experience of tension between the need for academic rigour and pragmatism. I remain intensely curious about the experience and self concepts of this client group. I feel that in future, I will be less easily daunted in pursuing answers to questions I feel to be valuable.

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Appendix A



**The
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10th September 2006

Julie Pehl

Dear Julie


I am writing to indicate our approval of the journal(s) you have nominated for publishing work contained in your research thesis.

Literature Review: Journal of Research and Intellectual Disability

Research Report: Journal of Research and Intellectual Disability

Please ensure that you bind this letter and copies of the relevant Instructions to Authors into an appendix in your thesis.

Yours sincerely


Andrew Thompson
Research Tutor

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A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address. A suggested running title of not more than fifty characters, including spaces; and up to six key words to aid indexing should also be provided.

Main Text

All papers should be divided into a structured summary (150 words) and the main text with appropriate sub headings. A structured summary should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study.

The text should proceed through sections of Abstract, Introduction, Materials and Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file. The reference list should be in alphabetic order thus:

Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.

McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.

Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

Illustrations and Tables

These should be referred to in the text as Figures using Arabic numbers, e.g. Fig. 1, Fig. 2, etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number.

Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Please save vector graphics (e.g. line artwork) in Encapsulated Postscript Format (EPS), and bitmap files (e.g. half-tones) in Tagged Image File Format (TIFF). Ideally, vector graphics that have been saved in metafile (.WMF) or pict (.PCT) format should be embedded within the body of the text file. Detailed information on our digital illustration standards is available on the Blackwell web site at <http://www.blackwellpublishing.com/authors/digill.asp>.

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Appendix B

Subj: FW: Ethics of "An Exploration of Therapists' Experience..."
 Date: 07/06/2006 15:57:59 GMT Daylight Time
 From: Julie.Pehl@derbysmhservices.nhs.uk
 To: juliemozzy@aol.com

-----Original Message-----

From: Paschal Sheeran [mailto:p.sheeran@sheffield.ac.uk]
Sent: 11 May 2006 10:00
To: Pehl, Julie; juliemozzy@aol.com
Subject: Ethics of "An Exploration of Therapists' Experience..."

Dear Julie,

Thank you for your submission to the Department of Psychology Ethics Sub-committee ("An Exploration of Therapists' Experience of Psychodynamic Psychotherapy with People with Learning Disabilities"). I spoke to Nigel Beal about your proposal, and he indicated that participants would not be recruited through the NHS and that data collection would not take place on NHS premises.

Assuming that these aspects of the procedure are accurate, then I am pleased to inform you that the ethics of your research are approved.

Yours sincerely,

Professor Paschal Sheeran
 Chair, Department Ethics Sub-committee

--

Paschal Sheeran, PhD
 Professor of Psychology
 Department of Psychology, University of Sheffield
 Sheffield S10 2TN, UK
 Phone: +44 (0) 114 222 6578
 Fax: +44 (0) 114 276 6515
<http://www.shef.ac.uk/psychology/staff/academic/paschal-sheeran.html>

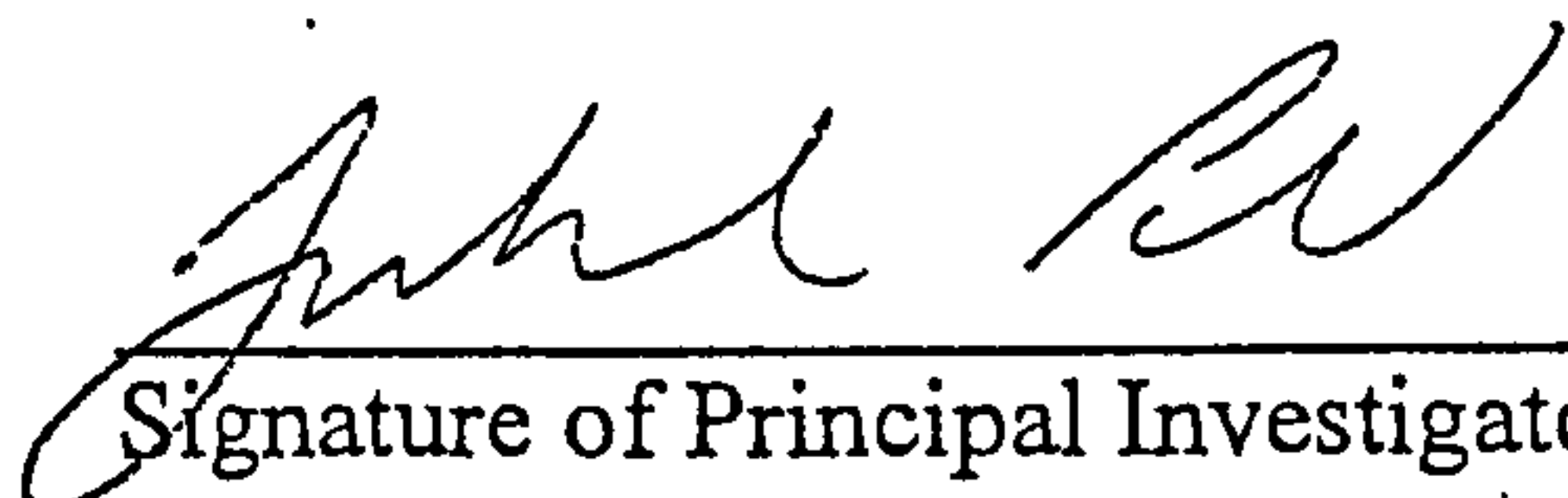
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By signing this page, the Principal Investigator acknowledges that:

1. They have read the Research Governance Framework
2. Agree to comply with the responsibilities of the principal investigator as set out in the Research Governance Framework



Signature of Principal Investigator

29.6.6
Date

JULIE PEITZ

Printed name of Principal Investigator

Please return completed form to
Corinne Gale
Mental Health Research Unit
Kingsway House
Kingsway Hospital
Derby
DE22 3LZ

Mental Health Services NHS Trust

Mental Health Research Unit

Kingsway House

Kingsway Hospital

Derby

DE22 3LZ

01332 623579

01332 623576

E mail: Corinne.Gale@DerbysMHServices.nhs.uk

22 June 2006

Outlook
99 Briar Gate
Long Eaton
NG10 4BQ

Dear Julie


RE: An exploration of the therapist's experience of psychodynamic psychotherapy with people with learning disabilities

I am writing to inform you that the Derbyshire Mental Health Trust Clinical Research Committee has been notified about the above study.

As part of the dissemination process within the Trust, please can you provide a short summary of your research findings once the study is complete.

If you require any further information please do not hesitate to contact me.

Yours sincerely



Corinne Gale
Acting Research Coordinator

Appendix C

Interview Schedule

1. How did you come to work psychotherapeutically with people with learning disabilities?

Why did you work with this client group?

2. Can you tell me about the first time you saw a client with learning disabilities?

What do you remember about your early contact with clients with learning disabilities? (If participants are unable to recall first contact)

3. Have you worked psychotherapeutically with any other client group?

What was that like?

4. What is it like working with clients with learning disabilities now?

Can you tell me about your recent experiences working with learning disabled clients?

5. Psychotherapists work within a model which identifies transference as part of the therapeutic relationship. Can you tell me what it's like working with transference with clients with learning disabilities?

Have you found this with other clients?

6. Whilst working in a psychotherapeutic model, we pay attention to counter transference. Can you tell me what you have experienced in counter transference whilst working with people with learning disabilities?

Have you found this with other clients?

7. How would you explain to a psychotherapist, who doesn't work with clients with learning disabilities, what it is like?

What would you tell them about your experiences?

Appendix D

THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)
 Clinical supervision training and NHS research training and consultancy

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TP UK

Telephone: 0114 2226649
 Fax: 0114 2226610
 Email: c.a.gillespie@sheffield.ac.uk

Julie Pehl
 C/o Erewash CTLD
 OUTLOOK
 99 Briargate
 Long Eaton
 NG 10 4BQ

Date: 19.6.6

Dear IPD member,

I am a clinical psychologist working with people with learning disabilities in Derbyshire. I have a particular interest in psychotherapy with this client group and am currently undertaking research on the topic as part of my studies for a post qualification Doctorate in Clinical Psychology (D Clin Psych.) at Sheffield University.

Under the supervision of Professor Nigel Beail, I hope to explore therapists' experiences of psychotherapy with people with learning disabilities. To this end, I am presently seeking participants who are willing to engage in an interview and share their experiences in this field.

I have enclosed an information sheet on the study. If you might be interested in participating in the study, I would be most grateful if you could contact me by:

Email - juliemozzy@aol.com
 or julie.pehl@derbysmhservices.nhs.uk

'Phone – 07792 314620

Or alternatively, you could fill in the reply slip overleaf and return it to me in the envelope provided.

pto

Thank you for your time,

Yours sincerely,

Julie Pehl, M.A., MSc. Clinical Psychologist

.....

Name: _____

I would be interested in participating / hearing more about the study.

I can be contacted on _____ (tel no.)

I would prefer to be contacted at the following days or times

THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)
 Clinical supervision training and NHS research training and consultancy

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TP UK

Telephone: 0114 2226649
 Fax: 0114 2226610
 Email: c.a.gillespie@sheffield.ac.uk

INFORMATION FOR PARTICIPANTS

Project Name: An Exploration of the Therapist's Experience of Psychotherapy with People with Learning Disabilities

Researcher: Julie Pehl, Clinical Psychologist, Postgraduate student on the Doctorate of Clinical Psychology Course, Sheffield University.

You are being invited to take part in a research study. The study is being undertaken as part of the requirements for my studies towards a Doctorate in Clinical Psychology at the University of Sheffield.

What is the purpose of the study?

To find out about what it is like to work therapeutically with people with learning disabilities.

Why might the study be useful?

There is currently only a small body of research investigating the therapeutic relationship with people with learning disabilities. This study would add to that body of research. In particular, there is a long tradition of people with learning disabilities being denied access to psychotherapy, so descriptions of the experiences of therapists may be valuable in investigating this issue further.

Who is taking part?

I am looking for 8 – 12 participants, who fulfil the membership criteria for the Institute of Psychotherapy and Disability (IPD), and work with people with learning disabilities within a psychodynamic model

What does it involve?

The study involves an interview in which I will be asking you to describe your experience of working therapeutically with people with learning disabilities. The interviews are expected to last between one to one and a half hours and will be taped. The tapes will be transcribed and main themes identified from the participants. The results will then be fed back to you in a phone call to check they accurately reflect your experiences.

Confidentiality

All information given will be treated as confidential. Tapes will only be heard by the research team. Nothing that can identify you or your clients will be included in the study report.

If, during the interview, a disclosure is made which may indicate abusive practise, this issue will be discussed with the research supervisor and may be referred on to an appropriate professional body.

What rights do I have if I agree to be contacted about participating?

If you agree, I will contact you by phone whereby you can ask further questions. An interview will be arranged at a time and place to suit you. Before the interview we will go over the information about the study and you will be given a consent form to sign. You will be able to withdraw at any time or decline to answer questions if you wish.

Any participant who was unhappy with their experience, has the right to make a complaint. A complaints procedure has been established by the University. In the first instance, complaints should be addressed to Professor Nigel Beail, Sheffield University Clinical Psychology Unit, Western Bank, Sheffield S10 2TP (0114 2226570).

Thank you for your time.

Appendix E

THE UNIVERSITY OF SHEFFIELD
Clinical Psychology Unit
Department of Psychology

Doctor of Clinical Psychology (DClin Psy) Programmes (Pre-registration and post-qualification)
 Clinical supervision training and NHS research training and consultancy

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TP UK

Telephone: 0114 2226649
 Fax: 0114 2226610
 Email: c.a.gillespie@sheffield.ac.uk

CONSENT FORM

Title of project: An exploration of the therapist's experience of psychotherapy with people with learning disabilities.

Name of researcher: Julie Pehl (M.A., MSc.,) Post graduate student, Sheffield University
 Doctorate n Clinical Psychology (D Clin. Psych).

1. I have read and understood the information sheet. _____
2. I have had an opportunity to ask questions and these have been answered. _____
3. I understand that the interview will be recorded, but that my identity will be kept anonymous in any material used. _____
4. I understand that I can choose whether or not to take part and that I am free to terminate the interview at any time. _____
5. I agree to take part in the above study. _____

Name of participant :

Date:

Signature:

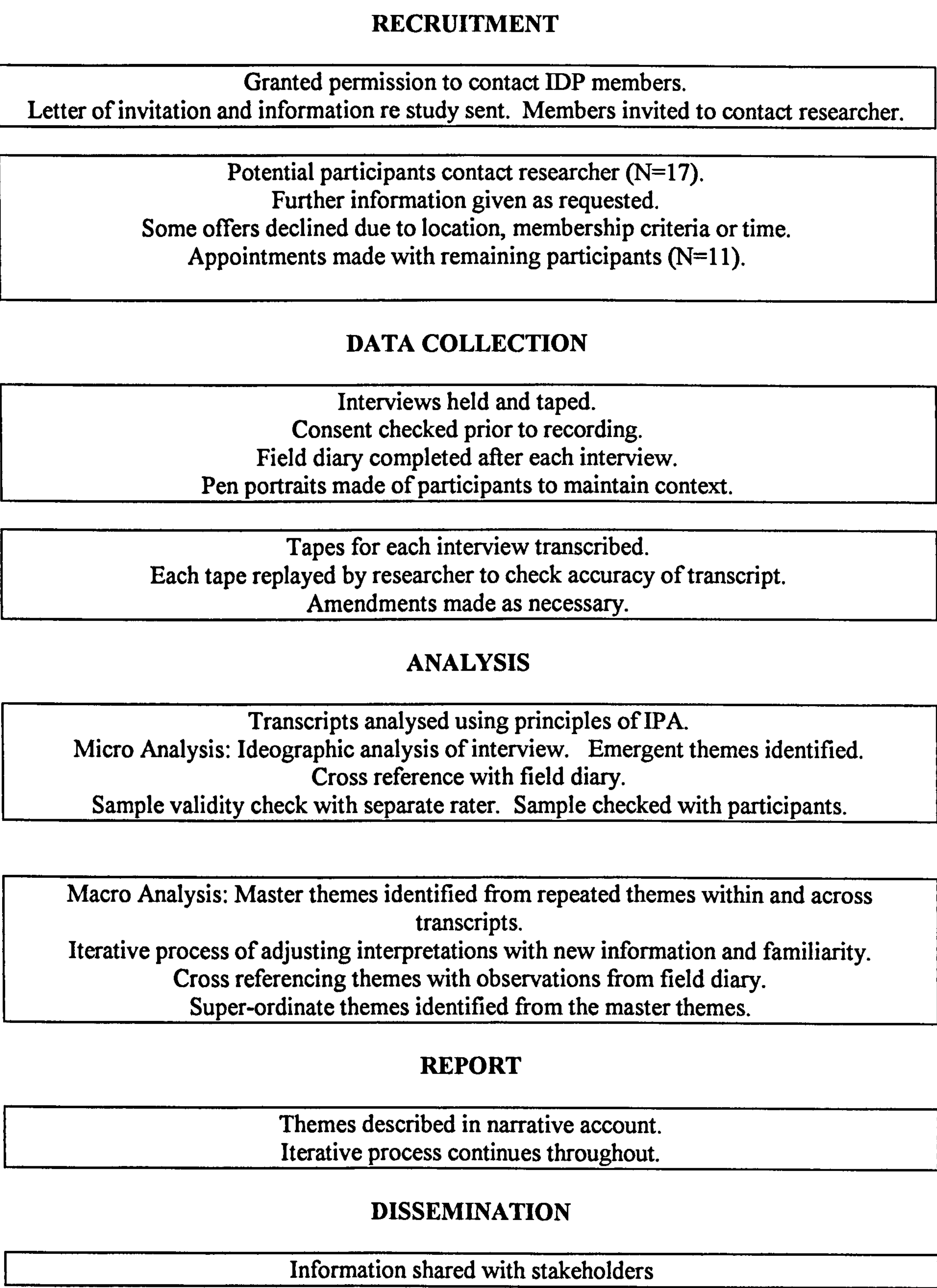
Name of researcher:

Date:

Signature:

Appendix F

Figure 8. Overview of the Research Process



Field Diary Excerpts

The following section illustrates the analytic process using examples drawn from a range of participants to demonstrate transparency of process.

Pre-transcription analysis: extracts from field diary

The following extracts are included to demonstrate the recommended process of keeping a field diary during the research process. The content of the extracts highlights the reflective process, with observations being made on the technical aspects of the interviews, the ethical issues involved, the awareness of the researcher's introjections, and the emergent themes across participants.

Graham's Interview

Graham warned me that he may "dry up" and requested prompting if necessary. In the event, I prompted minimally although I struggled not to ask questions about some interesting areas he described. Again, I am struggling with the distinction between "Funnelling" and "Leading", by choosing areas I may have a vested interest in. But I find it frustrating not being able to home in on something for fear of introducing too great a bias.

Interesting that transference not dealt with directly, - Different perspective due to working with young people? (7.8.6)

Alistair's Interview

Again realising that the counter transference issues were personal, and that I wanted to, and needed to, make some reflective comments to keep the "human" quality in the interview. Realised that it was a brave admission for the participant. I wonder if I have been a little blasé about the impact of the interviews? (8.8.6)

Example of Preliminary Analysis

- 225 and so he was talking about working with learning disability which is that's the
- 226 first time that's actually come into the main stream of the guild and people did
- 227 find it very hard, they
- 228 (21.8) were terribly moved by it but some people were angry and said how could
- 229 you call this psychotherapy and so I think sometimes people get very very
- 230 defensive.
- 231 That's interesting, erm is there anything when you're in that situation, you sound, its
- 232 like you've actually been in a situation of, you know, seeing an opportunity for
- 233 talking to others and focussing about it, or other people have, and I was wondering
- 234 what kind of feelings that invoked, you know?
- 235 To me?
- 236 Yes and so what sort of things you'd have liked to have said.
- 237 Erm I suppose I'd have liked to have said that in a way we are all working in a
- 238 field of learning disability because we're all trying to bring a sort of
- 239 understanding to somebody else's experience so its not that different and yes it's
- 240 a different degree but actually its what were all doing, so it's, one of the
- 241 criticisms was that with all this theory we're talking about its for your benefit,
- 242 not the client, because they can't really understand it, but I guess that would be
- 243 the case for all theory in a way - its for the therapists' benefit in that it helps
- 244 them to understand or defend against some of the material. I don't know, its
- 245 recognising how defended against it are people, again thinking back to
- 246 and how the battle that had, and the therapists maybe
- 247 more than most people, though they shouldn't be, are defended against the
- 248 reality of the messiness of it all, you know, - want to get into the sort of the high
- 249 flow of language, its very hard to stay with mopping up the mess.

Response of colleagues
Shame?

LD marginalised
professionally

Polarsad
reaction

discredit
excluding
therapists as
well as
clients
- threaten
professional
identity

Similarity & Difference - Overview

Universal experience
- incremental
sense of continuum
with underlying similarity

Professionals
agenda

what do
wish I'd have
said...

Therapists have
an agenda

No wish
The Real to know
Vs

don't
mention

- intellectual constructs / snobbery
vs reality & mess.

Representation Check

225 and so he was talking about working with learning disability which is that's the

226 first time that's actually come into the main stream of the guild and people did

227 find it very hard, they

228 (21.8) were terribly moved by it but some people were angry and said how could

229 you call this psychotherapy and so I think sometimes people get very very

230 defensive.

231 That's interesting, erm is there anything when you're in that situation, you sound, its

232 like you've actually been in a situation of, you know, seeing an opportunity for

233 talking to others and focussing about it, or other people have, and I was wondering

234 what kind of feelings that invoked, you know?

235 To me?

236 Yes and so what sort of things you'd have liked to have said.

237 Erm I suppose I'd have liked to have said that in a way we are all working in a

238 field of learning disability because were all trying to bring a sort of

239 understanding to somebody else's experience so its not that different and yes it's

240 a different degree but actually its what were all doing, so it's, one of the

241 criticisms was that with all this theory we're talking about its for your benefit,

242 not the client because they can't really understand it, but I guess that would be

243 the case for all theory in a way - its for the therapists' benefit in that it helps

244 them by understand or defend against some of the material. I don't know, its

245 recognising how defended against it are people, again thinking back to

246 and how the battle that : had, and the therapists maybe

247 more than most people, though they shouldn't be, are defended against the

248 reality of the messiness of it all, you know, - want to get into the sort of the high

249 flow of language, its very hard to stay with mopping up the mess.

oh
herosht
how
LD how

how call
you call
this
psychotherapy

rejection
as a defence.

all from
to bring
understand
to ensure
else experience

not the
different to
different
degree

there is in
the herosht

battle to
gain
recognising

defence against
the messiness.

mopping up the
mess

percept
reactive
or
other
matters
can
re
results

but
also
similar
be
understand
surveys
else
experience

what
to
map
no
reality

Macro Level Analysis

Individual master themes and models: At this stage, themes from the interviews were organised into initial master and subordinate themes. An example of this level of analysis is given below, drawn from Graham’s transcript:

Figure9. Early model of Themes from Graham’s transcript: Involvement, Differences and Similarities, & Role of Therapist.

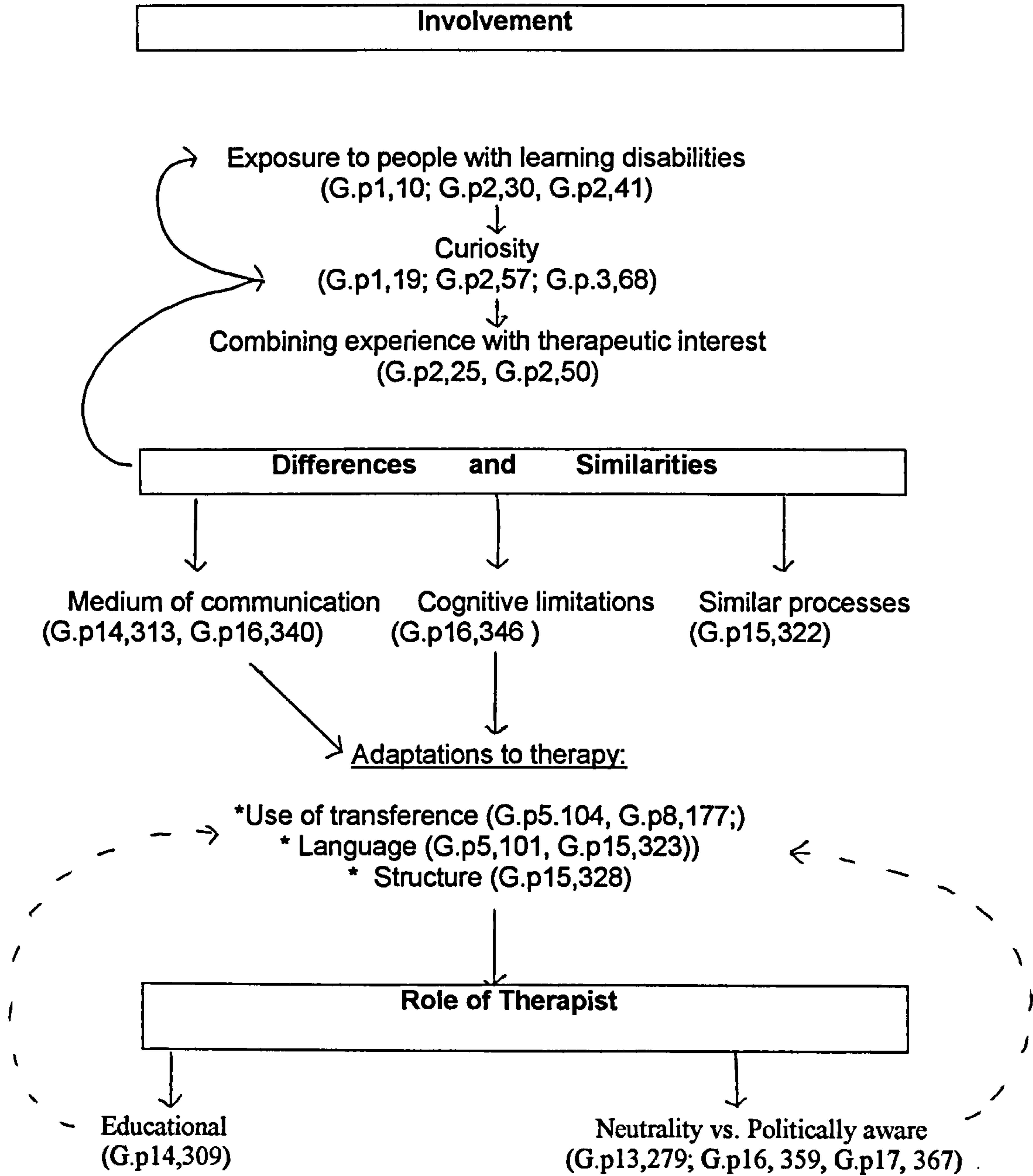
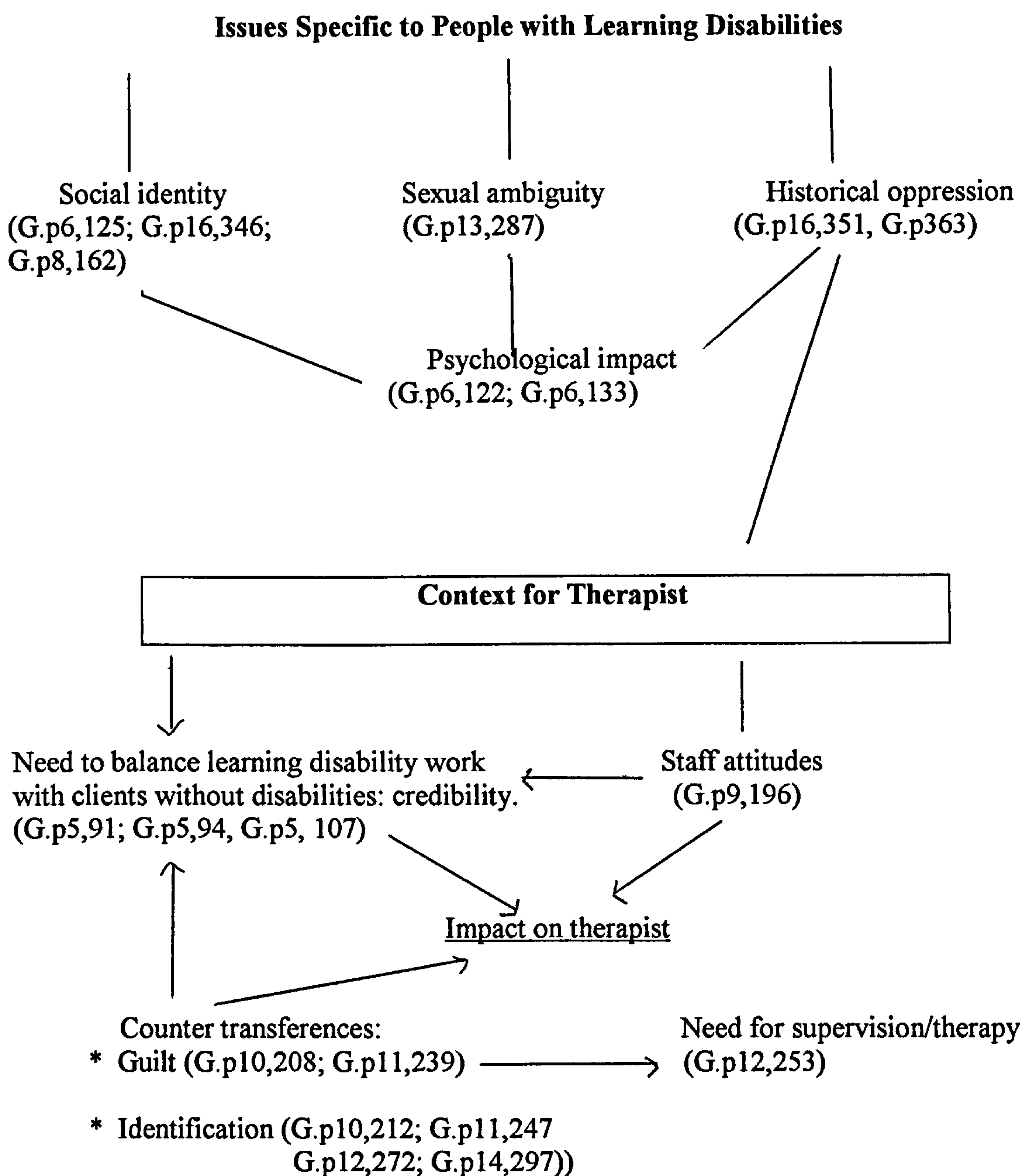


Figure 10. Early model of themes from Graham's transcript (contd): Issues Specific to People with Learning Disabilities, and Context for Therapists.



Participant Validation

Participant checks: These were included in order to address concerns regarding *representation*, i.e. to ensure that it was the participant's reality that was reflected in the research. The following is the written feedback emailed to Belinda, for her comments following individual analysis of her transcript.

EVOLUTION AS A THERAPIST –

You described early issues that shaped your career, including your wish to work with others who were disadvantaged.

I wanted, want to work with people who, who are in need, who are erm disadvantaged people so I think that's some of those strings pulling away at me.

You had early positive contact with people with learning disabilities and described being intrigued by the differentness of their world. You described an impactful early therapeutic contact and a curiosity about peoples' inner lives.

I was just absolutely intrigued by this other world, it was like erm, it was like a kind of another world, it was , it was like a almost like a old Victorian factory type of world and, and it was almost, I felt as if I had entered into a Dickens erm book erm where this Dickensian type characters that you don't really see out in the street erm and that really thinking back I mean were really segregated I mean you hardly saw people with learning disability out and about, erm and it was interesting.

One of the things that has stayed with me throughout these years has been the work that I did with John erm like I felt that erm it was, it was you know it had something to do with attachment, had something to do with bonding, erm it had something to do with erm you know sticking with somebody and engaging with them and them knowing that and feeling that and responding to that.

You explained how you became aware of the limits of "normalisation" as a model, and found yourself in a sympathetic environment which, almost accidentally fostered your interest in therapy.

If you could teach people and teach people to live independently and recreate their lives so you move them in, into beautiful flats that, with everything new, then it would put right everything that's happened to them. And it was er quite a simple idea and I, and we all kind of fresh and we all thought it was great idea at the time, (laughter).

I turned up at the door and she said I thought you were trainee psychologist, and I said no I'm a therapist and she said well it so happens, it was complete coincidence that er one of her psychologist who had been doing some therapy had left, and she really did want somebody to pick up the work.

You identified your willingness to take on a challenge.

I thought crikey can I do this, and I erm I, up for a challenge me so you know I took it on.

COMMON GROUND –

You noted similarities in therapy with clients with learning disabilities to other clients, with whom you had worked.

I guess for any therapist its like really about realizing its not hopeless and helpless and erm like with all counselling and therapy and psychotherapy its about finding your points of engagement erm which is necessary.

PARTICULAR ISSUES –

You identified a number of issues which were particularly represented in the clients you described. These included, experiences of abandonment, abuse, envy, lost histories and frustrated sexuality.

He was putting into me that uncomfortable sexuality that uncomfortable sexual feeling.

You noted that a major theme was the disability itself – and gave a powerful account of a client's ability to recognise how he was viewed as "monstrous" and "other".

This terrified him so much that his flat mate was calling him Frankenstein so it was why is he calling me but I could see for JT it was more than name calling it was something that he was living, it was like it was something that pulled at him, like it was more a reality.

NEED TO ADAPT THERAPY –

You identified particular ways in which you adapted techniques and mediums to meet the needs and limitations of your clients, including working in tandem with other staff outside the therapeutic environment.

It did help for me in this situation to bring with me the books without words.

What I found was effective is I'd put my hand over my mouth for quite a long period of time ...I wanted to do something quite symbolic to show him how it felt being with him when he wouldn't let me through. A piece of work with the community was quite helpful here, they went with him to visit his grandma where she was buried, and he found that a valuable experience.

PRESENTATION –

You described some of the ways in which your clients presented, which included the “handicapped smile”, going to sleep, concealing information, breaking boundaries of therapy and dominating sessions.

I’ve got many experiences of people with Down Syndrome the smile.

He was very strong powerful in the sessions in that he would monopolize.

USING THE BODY AS A MEDIUM –

You described the self injurious behaviour of clients who damaged themselves as a way of communicating, and intended or feared that they were intrinsically damaging to those they were around.

He picked at his cut on his finger, he picks his plaster away and gauging and gauging away at his cut, and it was absolutely unbearable to watch him do this erm and erm this when I told him how I felt he smiled and it was very painful as I felt that he was so disassociating really from the pain erm and he was watching my response and smiling at my response.

THE IMPACT ON THE THERAPIST –

You described the sense that the work was often difficult, particularly the pain of addressing the disability itself. You had experience of being verbally and emotionally abused and identified the physical impact of some sessions.

The thoughts came through my mind are that your saying I’m damaged and and that you can’t do anything about it can you erm and I’m going to hurt myself and continue to hurt you erm you know and that was very painful.

I did actually leave the sessions with a terrible headache and that has made me really wonder about the power, the intensity of these, of our relationship you know where your containing erm the fears you know real fears peoples negativity and how they are affecting other people erm and how powerful that is really so you can actually get physical ailments.

You also had to deal with maternal counter transferences, and experiences that were frightening.

I felt quite frightened sometimes.

EFFECTIVENESS –

Despite this, there was a sense of achievement in seeing improvement in clients, where you were able to provide a secure base, acceptance and rectify damaging experiences by your input.

It was like we had worked through something and worked through what she wanted to tell me and once she had told me that, that was enough.

THERAPISTS' ROLE –

You described how there was conflict between the philosophical “rights” position, and the work of the therapist.

Therapy is more concerned about finding out what's it like to be a person with learning disability and the exploration is about what its like for people and erm that might be at odds with human rights.

You gave examples where the care environment was actually damaging to the person.

There was something I felt quite perverse about the whole thing that really worried me, erm because on the surface of it, it was like an activity that you can do but on another level it was like really rubbing her in, rubbing the wound in.

You try to resolve this by working as a team to address issues outside the therapy space, whilst maintaining the therapeutic relationship.

There's two of us and we decide with each case whether we can do the network meeting and be quite strong voice for the other person so we are not going to compromise the relationship or whether we can do it ourselves.

POLITICAL –SOCIAL IMPLICATIONS –

You saw the role of the therapist as sometimes controversial because of the need to go against the community or services' agenda sometimes, and on a wider scale felt that therapy acted against the societal death wish for people with learning disabilities.

As a therapist its just being aware that there's another agenda that there's an outside agenda as well as the clients internal agenda its very strong.

We are actually opposed to erm something that is societies death wish and this idea generally that people that aren't perfect don't have a place in the world and we are working with people showing the world that actually people do have place in the world and enabling them to become erm more to find that space so its that structure as well in the therapy.

The openings to providing therapeutic opportunities, and a proper service for people was currently a little limited, but you were optimistic that things appeared to be improving.

Looking around there aren't any other therapy jobs in PLD and so it's a growing thing, I hope somewhere its going to flourish somewhere apart from here,

However, this client group was still avoided by others in therapeutic training.

I was quite surprised at the number of students of counselling erm that weren't wanting to work with this client group and the kind of responses I got I just wouldn't know how to work, I mean how do you do it, I mean how do you do it Alex and that sort of thing, and so the sense of hopelessness and helplessness.

Environments were not always supportive of psychotherapeutic ways of working and there was a sense of conflict between the agendas of the staff and the clients, and a lack of understanding of what counselling was.

There's hardly any self referrals its all via care managers, or erm nurses or homes or that sort of thing erm and its quite interesting because a lot of what we pick up is an agenda.

It feels like a strong battle erm particularly where this were there is also quite strong behavioural erm move and er in a secure unit where I have got some of my clients erm there is, the behaviour, the behavioural side of the psychiatric, medical side is very strong.

I find that erm even health staff, like community nurses erm er occupational therapist and speech therapist here you know, I though that they might know a bit about counselling but often people really don't.

"REAL" ISSUES

You noted that, like the broader political issues, there was also an external reality to some of the issues that might be seen as psychological.

In therapy I pick up what its like being the client like sometimes they can have bit of a moaning session about their workers and that's an interesting thing because I, I'm never sure whether its, whether its er the clients, what's going off in the clients in relation to their workers and erm there are times when I really do wonder whether, I mean, have evidence that the workers aren't really working kind of as well as they could be.

Participant Response

Managing subjectivity: Participant checks are used to control subjectivity and ensure appropriate representation. The following is Belinda's reply to the analysis.

Message

Page 1 of 1

Subj: **RE: feedback**
Date: 20/10/2006 10:57:20 GMT Standard Time

Dear Julie,

Thank you so much for this. I am very impressed by how you worked through my transcript and happy that my experience has been of value.

I have been very busy this week with some difficult situations in relation to my clients network. I have an example of the kind of situation I find myself in which I feel is encapsulated under the heading "you gave examples where the care environment was damaging the person". (Although I would not be able to put it like this myself to the carers, essentially this is what is happening).

A client of mine has become distressed over the fact that she has just found out that a member of staff within her home has become pregnant. She became immediately distressed and very sad because she has chosen not to have a baby because of the risks, (having had genetic counselling). The staff have said that everyone should be happy for the staff member and so my client avoids being at home as she feels very sad. While in a network meeting I explain the point that in order for my client to cope with her feelings, it is important for her to be able to mourn and feel sad at home, be supported in this. The point is barely heard and so I have to repeat this and explain the dynamics. There is then concern that the client has missed her contraceptive injection and so nursing say that they will have to deal with this, advise her to have it a.s.a.p. My concern at this point is the fact that insistence on the contraceptive injection is like "rubbing the clients nose" in the fact that she wants a baby but knows that it would be risky, and perhaps her contraception can wait until she has come to terms with her terrible distress, triggered by hearing the news about her carer.

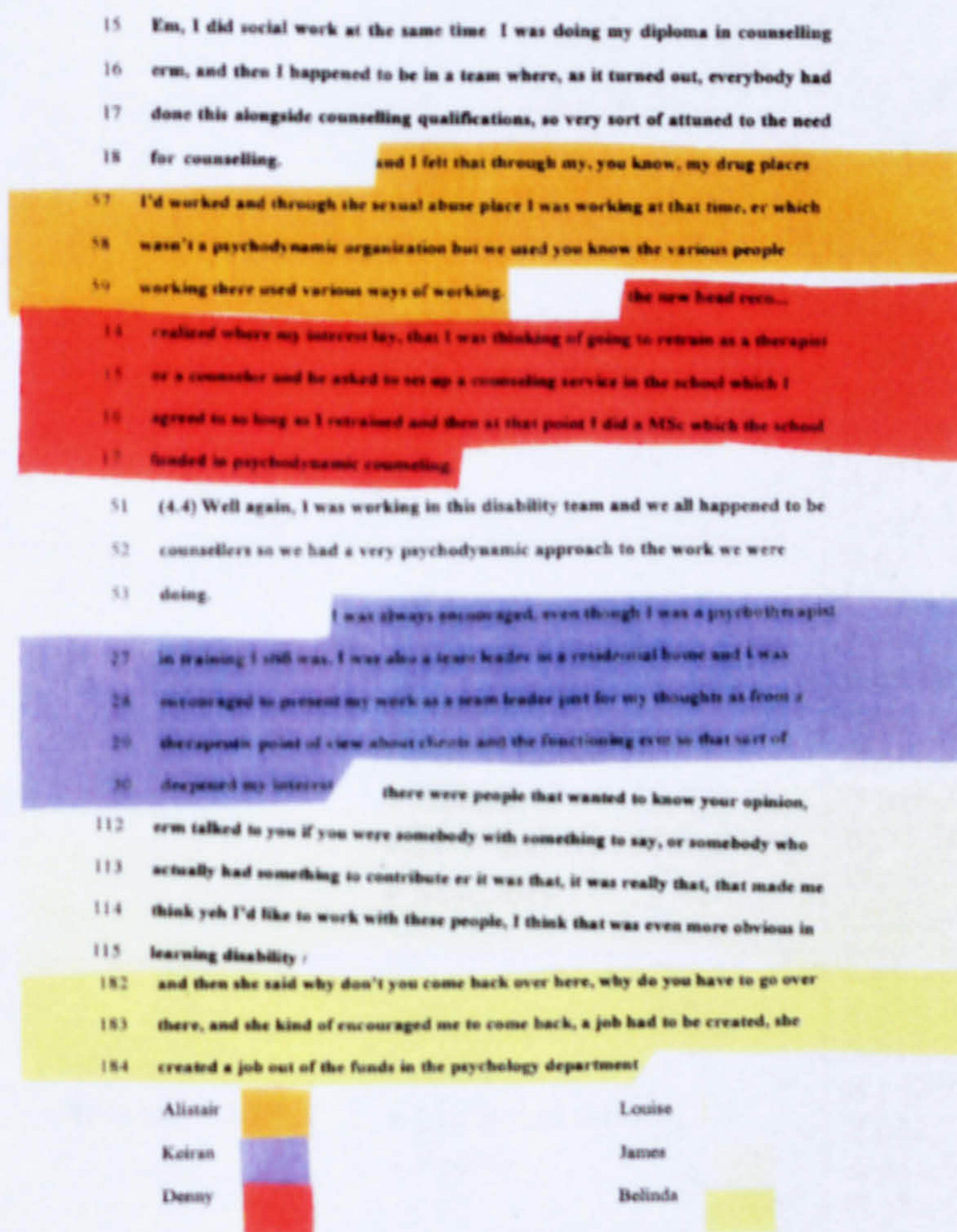
The need to gain control by the service was far more prevalent than thinking empathically about her situation.

Maybe there's also something about the therapist as advocate here also.

Hope all is well and look forward to hearing from you.

Identification of Super Ordinate Themes

Visual textual display: The following is an example of the cut and paste system used to identify areas common across participants.



The resultant super ordinate themes not displayed in the report are shown in Figures 10. and 11.

Figure 11. Super ordinate theme 1. with subordinate themes with textual references.

Super-ordinate Theme 1: Similarities & Differences		
Master Themes	Subordinate Themes	Sample Evidence
Common Ground	<ul style="list-style-type: none"> • Continuum Model • Universality of Principle • Emotional Intelligence 	L.p4,68; J.p17,369; D.p11, 231; P.p16,354; C.p23,517; D.p5,91; B.p42,957; L.p11,238 E.p5,107; P.p17,378 A.p15,317; L.p5,106 C.p16,353; C.p20,451;
Specific Issues	<ul style="list-style-type: none"> • Disability itself • Anger • Shame • Social Factors • Abuse • Loss and Abandonment • Sexuality 	B.p26,587; C.p23,519; D.p7,137; A.p9,197; G.p13,293; S.p12,253; P.p9,186; J.p19,427; E.p2, 40; P.p17,374; B.p11,229; D.p16,353; D.p16,353; B.p17,373; Bp25,569; D.p16,345; D.p15,321; C.p14,298; C.p22,487; D.p15,322;
Therapeutic Adaptations	<ul style="list-style-type: none"> • Use of counter trans. • Medium • Communication • Pacing 	L.p6,120; K.p11,228; P.p11,247; G.p5,104; S.p10,218. J.p8,167; B.p33,755; C.p2 45; E.p32,721; D.p9,190; A.p14,305; G.p9,187; C.p24,537; P.p9,218.
Primary Secondary & Tertiary Handicaps	<ul style="list-style-type: none"> • Primary versus Secondary handicap • Vulnerability to systemic abuse • Therapists role 	G.p15,328; S.p14,296; K.p13,274; C.p17,382; B.p21,482; A.p6,113; E.p17,375; D.p17,368; P.p10,217; J.p10 216; L.p12,271; S.p12,268; C.p22,504; P.p2,36; G.p9,195; D.p17,380;

Figure 12. Super ordinate theme 2. with subordinate themes with textual references.

Super-ordinate Theme 2:Working with Spoiled Identities		
Master Themes	Subordinate Themes	Sample Evidence
Evolution as Therapist	<ul style="list-style-type: none">• Early contact• Supportive Environment• Intellectual Curiosity• Mentor• Challenge• Unplanned career	D.p6,128; G.p2,30; S.p1,6; K.p1,6; L.p1,12; C.p4,79; J.p6,129; B.p1,5; A.p3,56; E.p3,67; P.p4,101; G.p4,78; E.p5,95; J.p2,35;
Courtesy Stigma	<ul style="list-style-type: none">• Exclusion from Training• Negativity from colleagues• Self-Consciousness	S.p1,15; C.p11,244; B.p41,932; L.p10,223; A.p3,60; K.p12,263; P.p16,360; J.p10,206; E.p16,353; G.p5,96; C.p22,493;E.p10,227.

Pen Portrait

Maintaining focus on the individual : The drawing of pen portraits of participants assists the researcher and readers to be aware of the context of the data produced. Whilst “thumbnail sketches” of participants were kept by the researcher, there were concerns that the small number of members of the IPD might mean that anonymity could not be guaranteed for participants with easily identified histories, or prominent roles. Therefore the portraits have not been included in the appendices, but an anonymised example of one of the participants is given below:

[X] is an [X] year old woman who currently lives and works in [City]. She is white and comes originally from [Region]. She took a degree in social sciences prior to starting work in a Social Services Training Centre, where her role was one of teaching occupational skills. She progressed through management roles, but pursued psychotherapy training after spending time observing other therapists at work. She completed a counselling qualification and worked initially with [client group]. She later combined this with her learning disability experience after she was unexpectedly offered the opportunity to see clients with learning disabilities following her training. She now works as a full time counsellor in a learning disability service in [District] and has held this role for X years.

Appendix G

THE UNIVERSITY OF SHEFFIELD
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01.6.6

Dear Simon,

Thank you so much for your help with my research. Our meeting was very useful.

We said that I would write up what you said, so you could make sure I had got it right. So, the main points I think you made were:

1. What do you think about what I am doing?

It is worth doing, because people with learning disabilities often do not get the same choices as everybody else. Sometimes people don't get a choice because people say a therapy won't work because of learning disabilities, but this might not be true all the time.

2. What do you think about how I am doing it?

Although it is an OK first step to talk to therapists, in the future, studies should be done asking people with learning disabilities about what it feels like for them. The report needs to explain why they were not asked first.

It might also be good to talk to therapists who do not work with people with learning disabilities, to ask why.

The therapists need to sign a consent form to show they agreed to take part. People reading the report need to know what questions were asked.

It would be interesting to know whether the therapists chose to work with people with learning disabilities, or if they felt they had to.

3. *Should I do anything differently?*

No problems with the way it is being done.
The questions seemed reasonable.

4. *Does it treat people with learning disabilities properly?*

It is important to use respect when talking about people with learning disabilities. There are words that should not be used in the report – words that are insulting (*you read out a list for me to note*).

I thought about this some more after we talked. I realised that I will have to put in what people wrote a while ago. This means that they may use words that now feel insulting. I do have to put down exactly what people said, but I can point out that this is not what we would say now.

Also, in finding out why therapists might find it hard to work with people with learning disabilities, I am going to have to talk about things that might be painful to think about. I hope you agree that trying to show an honest picture of what happens is a way of being respectful to people with learning disabilities.

5. *How should I involve people with learning disabilities?*

Results should be fed back to the Self Advocacy Group, the Quality Forum, along with the people who took part. The Advocacy service might like to know too. I will also go over the report with you, to get your comments and make any changes we think we should.

6. *Have you got any other comments about it?*

People who have severe learning disabilities might be left out. It might be that there are some people who can't use talking therapy. You could have people in to support them, but the carers might answer the questions.

It would be interesting to do another study looking at service user views and people who choose **not** to work with people with learning disabilities. Maybe a three way talk between all the groups would be interesting.

It would be good to get a mix of men and women in the study, but this might not be possible because lots of psychologists are women – but that would be another study question itself as to why!

I hope that I have got right what we talked about. You also gave me some helpful information from your educational talk about people with learning disabilities.

I aim to take notice of what you said as I do the study, especially when I write it up. You thought it helpful for me to include the number of people with learning disabilities in the report, and I will try to do this. I know you were keen to include the numbers of people locally, but to keep from letting on where I am based; I didn't think I would be able to do that.


However, you gave me some very valuable suggestions for web sites and government papers to look at. I will be using those suggestions in my research around the study.

So, once again, thank you very much for your time and help. It has been really useful. If you think I have got things right in this letter, could you sign the bottom and send it back to me? I have put an envelope in with the letter. If I have missed important points, or got something wrong, could you ring me to let me know? We can always change it until I get it right.

Many thanks,



Julie Pehl


S J RATCLIFFE



THE UNIVERSITY OF SHEFFIELD

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24.10.6

Dear Simon,

Thank you again for your comments at our meeting last week. We said that I would write up what we talked about. Here are the main points of what people said:

People had talked about how people with learning disabilities were the same as everyone else in lots of ways.

- They had the same problems.
- They could feel things just as deeply, and be very smart about knowing how they felt.
- All therapy is about talking to people trying to understand their problems – that's the same for anybody.

Some things were different. People with learning disabilities had some problems that came up a lot:

- They felt bad about having a learning disability.
- They had often been treated badly because of it.
- They were angry and ashamed.
- They had to rely on other people.

People showed how they felt in different ways.

- They showed how they felt rather than talked about it.
- They sometimes used their bodies to show things.
- They sometimes broke the rules – (you said how someone might walk around instead of sitting down).

Therapists had to change how they did things.

- They might go slower.
- They used easier words.
- They might not talk. They might draw or use things instead.
- They might not use a special room.
- They used how *they felt* to try and understand - (like you said about picking up someone else's mood).

THERAPISTS TALKED ABOUT WHAT IT WAS LIKE WORKING WITH PEOPLE WHO GOT LOOKED DOWN ON:**They said how they got to do their jobs.**

- They had all known people with learning disabilities before.
- They were interested in understanding.
- They worked in places that thought it was a good idea to talk to people.
- They found out about the work from a book or a person.
- They were not scared of trying something that might be hard.
- They thought it was worth it.

They said how it made them feel.

- They said it was hard when people showed things differently or did not follow the rules.
- They sometimes felt angry, or sleepy or stupid.
- They sometimes felt like they wanted the person with a learning disability to go away.
- They sometimes felt disgust with what people did.

We talked about these, because you had been worried before about people being treated properly, and not being called names. I explained that I felt that people were being honest as part of understanding the person they were with.

We talked about how other people feel the same things, but do not try to understand them – they just treat people badly. You said how you had seen that yourself.

They said how they got treated like their clients.

- People treated their clients badly.
- People were not interested in their work.
-
- They could not get training very easily.

They had to choose how to work with people.

- It was hard to know what things they could help with and what they could not.
- They had to take care not to treat people badly – making sure the person wanted to see them.
- They had to decide whether to help people speak out.

We talked about how I could tell other people about this, and we agreed to make sure I told the people we agreed on before. You reminded me that it was important that the people who talked to me got the results.

We talked about the need to ask people with learning disabilities what they thought and I agreed to put that in the report.

You made a very interesting point about whether people with learning disabilities could become counsellors, if they had support. I thought that some courses might be too hard because of the reading and writing. But others might be possible with help.

I also thought that people with learning disabilities could be helpful to each other even without training, because they could feel as well as other people.

I hope that I have put everything down that we talked about. If I have forgotten anything or got it wrong, please let me know. If I find anything else important, I will let you know.

Thank you again for all your help.

Best wishes,

Julie Pehl.